

Public Benefits 2019

A Resource Guide for Families of
Young Adults with Intellectual /
Developmental Disabilities (I/DD)



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INTRODUCTION

The purpose of this Guide is to provide information for families of individuals with intellectual and developmental disabilities (I/DD) about the public benefits that are of particular interest to this group.

It's important to know that people with I/DD have all the same issues as other people. Some are poor, some more affluent. Some are immigrants, some are native born. This manual will focus on the benefits for which people are eligible due to disability.

ADDITIONAL RESOURCES

Some of the information included in this guide is publicly available. Wherever possible, we have tried to identify these sources in each section. Any omission is unintentional.

There are a number of organizations that provide education and advocacy services to the I/DD community. You may find additional information online at the links below. This list is by no means all encompassing.

Arc of Illinois - <https://www.thearcofil.org/>

Family-to-Family Health Information Center - <https://www.familyvoicesillinois.org/>

IPADD (Illinois Parents of Adults with Developmental Disabilities) - <https://www.ipaddunite.org/>

McManus Consulting - <https://www.facebook.com/EdMcManusDDC/>

Rubin Law - <https://www.rubinlaw.com/>

We have also included a number of websites throughout the document. There may be times that the URL for the link has changed. Please contact us at training@dupagefederation.org if you discover a broken link.

Sam's Journey with Public Benefits

Sam is thirty-five and lives with his parents, Mary and Joe. He has Down syndrome, with moderate intellectual disabilities.

When Sam turned eighteen, his mom applied for Supplemental Security Income for him. His SSI check was reduced by one-third because he was considered to be 'living in the household of another'. He received \$517 per month.

When Sam was twenty, his mom went to a workshop on public benefits for persons with disabilities, and learned that if Sam was paying his share of the housing and food costs, there would be no reduction. Mary began documenting that Sam was paying one-third of the rent, utilities and food costs. She provided this documentation to Social Security, and his monthly check was increased to \$771.

When Sam turned twenty-six, the family's health insurance company notified them that he had reached the maximum age to be included on their policy. His parents provided documentation to the insurance company that he had a disability that had started in childhood and prevented him from working to support himself. The insurance company allowed Sam to remain covered on his parents' policy.

When Sam was thirty, his Dad reached his full retirement age and retired. When his Dad applied for his own Social Security benefit of \$2800 per month, he provided documentation of Sam's disability. Social Security approved Child Disability Benefits (CDB) (also known as Disabled Adult Child/DAC benefits) in the amount of one-half the amount that Dad was receiving, or \$1400. Because his Social Security benefit was greater than his SSI check, SSI was discontinued.

After Sam had been receiving benefits as a Disabled Adult Child for twenty-four months, he received a Medicare card in the mail. He received Medicare Part A with no premium, but had to pay \$135.50 per month for Medicare Part B.

A few months ago, Sam's Dad passed away. Shortly after, Sam was approved for funding in a Community Integrated Living Arrangement (CILA), funded by the State's Medicaid Waiver. Because Sam meets the requirements as a Disabled Adult Child, he is eligible for Medicaid, even though he no longer receives SSI.

Illinois System

The Illinois Department of Human Services – Division of Developmental Disabilities (DDD) manages funding and benefits for persons with intellectual and developmental disabilities. Services are funded through Medicaid Waiver Programs and are available through residential settings or provided in-home through the Home-Based Services Program. Residential services are provided in Community Integrated Living Arrangements (CILA) or through Intermediate Care Facilities for Individuals with Developmental Disabilities (ICFDDs). See page 40 for more information about these services.

The first step families should take are to connect with their regional Pre-Admission Screening/Independent Service Coordination (PAS/ISC) agency. The PAS/ISC agencies are responsible for intake for persons needing services and to coordinate those services once enrolled. PAS agencies also provide Individual Service and Support Advocacy and should be meeting with individuals four times a year to see that needs are being met.

As of July 1, 2019, the number of PAS/ISC agencies and the regions they serve have changed. A number of lawsuits filed challenging the changes. As of the writing of this manual, the new ISC system is moving forward. For more information about the ISC Transition, see <http://www.dhs.state.il.us/page.aspx?item=116491>.

To locate the PAS/ISC agency in your area, call 1-888-DDPLANS (888-337-5267).

PUNS List

The Prioritization of Urgency of Need for Services (PUNS) list is a database of Illinois infants, children, adolescents, and adults with developmental disabilities who have needs for developmental disability services or supports. The PUNS database helps the DDD identify and plan for individuals' immediate needs (Source – dd.illinois.gov).

Registering with the PUNS list is the first step a family should take, regardless if services are needed now or in the future. A PAS/ISC agency can help with this process. You may find more information online at <https://www2.illinois.gov/sites/dd/Pages/SignUp.aspx>

The PUNS database is used by the State to select individuals for services as funding becomes available, and for program planning. Services and supports for individuals with I/DD may include:

- In-home supports to help them live more independently

- Respite care to provide temporary relief to caregivers
- Training programs to teach life and work skills
- Residential living arrangements
- Adaptive equipment
- Other supports to improve quality of life

Families should enroll their eligible family member in PUNS to help identify service needs and to be placed on a waiting list for services. Individuals can enroll in PUNS at any age if they have developmental disabilities and are in need of services or supports. PUNS enrollment should be completed by an Independent Service Coordination (ISC) Agent.

Unfortunately, Illinois has a long waiting list for children and adults with DD. Advocates tell families to be prepared to wait even after the child is finished with school. Many families need to develop other plans while they wait for funding or wait for their adult to be pulled from the list.

PUNS selections are based on funding availability and considers criteria such as length of time on the list, urgency of need and geographic area of the state. Individuals will be informed if they are selected through a notice from the Illinois Department of Human Services. Individuals should then contact their PAS/ISC agency to apply for services. The PAS/ISC Agency will conduct an interview and identify the need for services in one of three categories:

- Emergency – the person needs immediate services
- Critical – the person needs services within one year
- Planning – the person needs services in 1-5 years

There are times that families encounter a crisis that will result in immediate placement. Examples of crises include death of a caregiver, caregiver is no longer able to address the individual's needs, abuse (physical, mental or sexual), homelessness, or individual is demonstrating behaviors that put the individual or family members at risk of serious harm. The first step to contact the local ISC agency for assistance in identifying the available options in their area.

The DHS-contracted Independent Service Coordination (ISC) agencies are responsible for screening individuals for eligibility for these services. As of July 2019, the funded ISC agencies and regions that were awarded the ISC contracts have changed.

As of July 1, 2019, the ISC Agencies are:

- Service, Inc. of Illinois
- Community Alternatives Unlimited
- Community Service Options

- Suburban Access Inc.
- Prairieland Service Coordination Inc.
- Champaign County Regional Planning Commission
- Central Illinois Service Access
- DD Services of Metro East
- Southern Illinois Case Coordination Services

To see what region of the state each ISC agency covers and for more information about the transition, visit the DHS website at <http://www.dhs.state.il.us/page.aspx?item=116491>.

1) Income

Objectives: Income

- Understand the differences between SSDI and SSI
- Know how to file for SSI
- Be aware of what is required to continue SSI when child reaches age 18
- Identify if SSDI is DAC benefit
- Explain DAC designation by SSDI and impact on medical coverage through Medicaid

Social Security Retirement, Survivors, & Disability Insurance (RSDI)

The purpose of ‘regular’ Social Security benefits is to replace income lost due to death, disability or retirement. A person is “insured” if they have earned sufficient work credits through the FICA tax system. Since these are earned benefits, there are no limits on an individual’s income or resources to qualify for regular social security benefits.

A monthly cash benefit is received once approved. *The amount a person receives varies based upon the lifetime earnings and length of time worked of the beneficiary.* Make use of the [My Social Security](#) option to register and review work history and possible benefit amount. The Social Security website may be used to estimate benefits the individual may receive <http://www.ssa.gov/estimator/>.

Overall Eligibility for Social Security RSDI

Social Security is generally available to:

- Retirees at age 62 (reduced benefit) or at their Full Retirement Age;
- Persons with disabilities regardless of age whose disability is expected to last at least 12 months or result in death;
- Surviving widows or widowers and dependent children;
- The spouse of a retiree who is at least 62 years old.

Individuals with Intellectual and Developmental Disabilities (IDD) may qualify for ‘regular’ Social Security in several situations:

- When their parent(s) start receiving Social Security due to disability or retirement, the son or daughter with disabilities can receive monthly benefits as a disabled adult child;
- When their parent(s) die;
- When they work and earn sufficient credits;

To qualify for retirement benefits, the worker has to have worked in covered employment for at least ten years and earned forty work credits. Auxiliary benefits for a spouse or dependent, including a 'disabled adult child' may also be available.

To qualify for disability benefits the individual must have a sufficient wage history based on years worked, age disability began and work history prior to the onset of the disability. To find out more about the disability benefit check out [Social Security Disability Benefits](#) in this manual.

More information about each program (Retirement, Survivors, and Disability) is provided below.

Application

Application for all Social Security benefits can begin on-line at www.ssa.gov.

- Click on the link for the appropriate program and enter the required information.
- Always print a copy of the confirmation page showing the application was submitted.
- Social Security will email a notice saying the application was received.
- Social Security will contact the individual if more information is needed.

If the individual has questions, contact Social Security at 1-800-772-1213. Individual may also go to their local Social Security Field Office. It is best to call the 1-800-772-1213 number to make an appointment. To find the office nearest to the individual's home <https://secure.ssa.gov/apps6z/FOLO/fo001.jsp>.

Social Security Retirement Insurance

The starting point for understanding Social Security is the Retirement insurance program. This benefit is intended to partially replace income lost due to retirement from employment. Other programs operated by the Social Security Administration are intended to partially replace income lost due to disability or death.

Full retirement age is the age when a person qualifies for full Social Security retirement benefits. This age varies based on year of birth. Currently, the full benefit age is 66 years for people born between 1943 and 1954, and it gradually increases based on year of birth to 67 for those born in 1960 or later.

A person may file for early retirement at age 62, but the monthly benefits are reduced, depending on their age at time of filing. This is a lifetime reduction and the monthly benefit does not increase once the person reaches their full retirement age. Conversely, if the worker delays receiving benefits to a date after the full retirement age the amount received will increase 8% each year delayed up to age 70.

Dependent (Auxiliary) Benefits - Retirement

When a worker retires, his or her dependents may be eligible to receive dependent (auxiliary) benefits. Social Security determines whether the dependent can receive a higher benefit on their own wage history or as a dependent. Sometimes people with disabilities can start out receiving benefits on the parents' record as a 'disabled adult child', and then later become eligible through their own work record. The dependent is issued the higher benefit amount.

Persons who may be able to get dependent/auxiliary benefits are:

- A spouse who is at least 62 years of age or younger if caring for dependent children
 - dependent children are children under age sixteen or **a disabled child regardless of age;**
- Dependent children up to age nineteen (if attending High School);
- **Disabled dependent children, who are adults who were disabled prior to age 22.**

Social Security rules limit the total amount of benefits that can be paid to families and dependents. The limit varies, but is generally between 150 and 180 percent of the benefit amount issued to the wage earner.

Example: Sam has been receiving SSI of \$771. Sam's father recently retired and filed for his Social Security Retirement. Sam's father will be receiving a monthly retirement benefit of \$2,800/month. Social Security approved Child Disability Benefits (CDB) for Sam. Sam is told he will be able to receive DAC benefits of \$1,400/month. Sam's SSI will end since the CDB rate is a greater amount.

NOTE: see page 20 to see how Medicaid coverage may be affected.

For more information: <https://www.ssa.gov/benefits/retirement/>

Social Security **Survivors Insurance**

When a wage earner dies, certain members of the family may be eligible for survivors' benefits.

A **widow/widower of an eligible worker** may receive full benefits at full retirement age, or reduced benefits as early as age sixty. If the individual receives widow's or widower's benefits, and will qualify for a retirement benefit that is more than the survivor's benefit, the individual can switch to his own retirement benefit as early as age 62 or as late as age 70. The rules are complicated and vary depending on the situation, so talk to a Social Security representative about the options available.

Example: Jill, age 60, is unemployed and needs an income. Her husband died three years ago. She is able to apply for survivors benefits and receive those until she is eligible for retirement benefits based on her own earnings.

Disabled widow/widower of an eligible worker – If the widow(er) is at least age 50 but not yet age 60 and they meet the disability criteria, they may receive survivor's benefits. The widow(er) cannot be entitled to their own disability benefits.

Example: Martha, age 50, is disabled. She has been a stay at home parent who just recently reentered the workforce so she has only four years of Social Security credits. Her husband died last year. She is able to apply for disabled survivors benefits based on her deceased spouse's earnings since she does not have the required 10 years of work under her own wage history.

Widow/widower of an eligible worker at any age if they care for the deceased worker's child who is under age sixteen, or child of any age if **disabled** and receiving Social Security benefits

***Example:** Rebecca, age 57, recently became unemployed and now cares for her son with developmental disabilities, who is 23. Her husband died three years ago which resulted in her son receiving Disabled Adult Child benefits based on his father's work record. Rebecca can contact Social Security to receive benefits for herself.*

Surviving children of an eligible worker may receive survivor's benefits if the following conditions are met:

- The child is under age 18;
- The child is under age 19 and a full-time elementary or secondary student; or
- The child is age 18 or over and has a disability (which began before age 22); and
- The child is not married.

***Example:** John died three years ago leaving Mary to raise their two children ages fifteen and twenty-three. The fifteen-year-old receives dependent social security survivor's benefits until age nineteen or high school graduation, whichever comes first.*

The adult son or daughter of an eligible worker who became disabled before age twenty-two and remains disabled is eligible for benefits on the parent's account. This is called Child Disability Benefits or Disabled Adult Child Benefits.

***Example:** Steve, age 23, who has severe cerebral palsy, was receiving SSI since age 18. His father recently passed away. Steve can apply for Social Security benefits based on his father's work history. If eligible he would receive the Disabled Adult Child benefit. If this benefit is more than the SSI benefit amount the SSI would stop. If Steve was on Medicaid for his health coverage, he could continue this coverage through the [Aid to the Aged, Blind or Disabled program](#).*

For more information:

<https://www.ssa.gov/benefits/survivors/>

SSA Publication: *Benefits for Children with Disabilities* - <https://www.ssa.gov/pubs/EN-05-10026.pdf>

Social Security Disability Insurance (SSDI)

Social Security pays disability benefits if the eligible worker cannot work because of a medical condition that is expected to last for at least one year or to result in death. Medicare coverage is available 25 months after receiving SSDI.

To apply for this benefit, medical records must be provided that include information about the individual's diagnosis, prognosis, symptoms and impact the illness/disability has on the ability to work.

When applying for Social Security Disability Insurance, it is important to provide accurate information about how the illness or condition affects the individual's ability to work. If the disability is due to mental illness, it is also critical to document how the illness affects four key areas of mental functioning:

- Understand, remember, or apply information
- Interact with others
- Concentrate, persist, or maintain pace
- Adapt or manage oneself

DO NOT assume that Social Security knows how an illness affects the individual's ability to work, as the impact is individual.

An Adult Child can work and earn credits on their own work record as long as they do not have substantial earnings. In 2019, they can work earn up to \$1,220 a month. In addition, Social Security's Ticket to Work Program provides income protections for workers with disabilities. See page 35 regarding Employment Programs.

For more information:

SSA Publication – *Working While Disabled: How We can Help* - <https://www.ssa.gov/pubs/EN-05-10095.pdf>

Dependent (Auxiliary) Benefits - SSDI

Similar to the retirement benefits, when a worker qualifies for Social Security Disability benefits, his or her dependents may be eligible to receive dependent (auxiliary) benefits. Social Security determines whether the dependent can receive a higher benefit on their own wage history or as a dependent. Sometimes people with disabilities can start out receiving benefits on the parents' record as a 'disabled adult child', and then later become eligible through their own work record. The dependent is issued the higher benefit amount.

Persons who may be able to get dependent/auxiliary benefits are:

- A spouse who is at least 62 years of age or younger if caring for dependent children
 - dependent children are children under age sixteen or **a disabled child regardless of age;**
- Dependent children up to age nineteen (if attending High School);
- **Disabled dependent children, who are adults who were disabled prior to age 22.**

Social Security rules limit the total amount of benefits that can be paid to families and dependents. The limit varies, but is generally between 150 and 180 percent of the benefit amount issued to the wage earner.

For more information:

<https://www.ssa.gov/benefits/disability/>

Supplemental Security Income (SSI)

Supplemental Security Income (SSI) provides help to people who are aged (65+), blind, or disabled and who have little or no income. It provides cash assistance to meet basic needs for food, clothing, and shelter. It is a separate program from Social Security Disability Insurance, but is often confused with it. The U.S. Social Security Administration manages both 'regular' Social Security and SSI. SSI is funded through the General Revenue Fund, not through the Social Security Trust Fund (FICA taxes).

Income and Resource Limits

Income must be at or below the [Federal Benefit Rate](#). The rate changes each year. If a parent is applying for a child under age 18, the parent's income and resources are considered. If the applicant is married, the spouse's income and resources are considered.

To be eligible for SSI, the individual is limited to no more than \$2,000 in available resources. A married couple may be eligible for SSI if they have resources worth no more than \$3,000. Countable resources include cash, bank accounts, stocks, bonds, land, life insurance, personal property, real estate, vehicles and anything else owned which could be changed to cash and used to pay for shelter. If the individual owns property that is to be sold, SSI may be received while trying to sell it in certain situations.

Certain resources do not count for SSI. Some examples include the home the individual lives in, household goods and personal effects, burial spaces, burial funds and life insurance policies valued at \$1,500 or less and one vehicle. Visit <https://www.ssa.gov/ssi/text-resources-ussi.htm> for more information.

Once approved, the individual receives a monthly cash benefit. The amount is set by federal law and changes each year. In 2019, the maximum a person can receive through SSI is \$771/month. Living arrangement can affect the amount a person receives.

Eligibility for SSI

In addition to having very low income and limited resources, the applicant:

- Must live in the U.S. and be a U.S. citizen, or qualified non-citizen.
- Apply for Social Security or other benefits. Individuals can get SSI and other benefits if eligible for both, as long as the regular Social Security Insurance benefit is less than the SSI benefit.
- If a U.S. veteran, the individual is also required to apply for [Veteran Benefits](#).

SSI for Children

Children under age 18 may be medically eligible due to their disabling condition. However, parents' income and resources are "deemed." Many children do not receive SSI as a child due to this counting of their parents' incomes. At age 18, they should reapply as an adult. One of the considerations when turning 18 is living arrangement.

Regardless of disability, Social Security looks at one's living arrangement to determine the amount of SSI someone will receive. Any food or shelter provided by someone else may reduce that SSI benefit for adults (age 18+). However, if an SSI recipient is paying their "fair share", they are able to receive the full benefit amount.

Example: Tony lives with his brother and two uncles in a home that his brother is buying. Tony's only income is SSI. There are four people in the home. The mortgage payment is \$1,300/month. Average monthly bills are \$200 for electricity, \$100 for water and sewer and \$600 for food. The total monthly expenses are \$2,200. Since there are four people in the home, Tony's share of the expenses is \$550.

If Tony can show he pays his full share, there should be no reduction of his benefit and he will receive \$771 in his monthly benefit. If he pays less than \$550 – SSA considers this in-kind support and maintenance. Tony's benefit would be reduced by one-third and he would receive \$514/month.

For more information about SSI and Living Arrangements:

- <https://www.ssa.gov/ssi/text-living-ussi.htm>
- <https://www.ssa.gov/ssi/spotlights/spot-living-arrangements.htm>
- <https://www.ssa.gov/ssi/spotlights/spot-one-third-reduction.htm>

For children receiving SSI, the transition from child benefits to adult benefits has some key considerations. The Social Security definition of disability for children is different than the definition for adults. The definition of disability for children is:

The child must have a physical or mental condition(s) that very seriously limits his or her activities; and the condition(s) must have lasted, or be expected to last, at least one year or result in death.

As an Adult, that definition shifts from a limit on activities to the inability to work. A Continuing Disability Review will be completed automatically at age 18 to see if the person is eligible for SSI under the adult definition. There are times where someone may have been medically eligible under the child definition but they do not meet the medical criteria as an adult. For more information about what medical evidence is needed for the disability evaluation process under Social Security, you may review the listings of impairments online at <https://www.ssa.gov/disability/professionals/bluebook/index.htm>.

During the Continuing Disability Review, Social Security will also review income, resources and living arrangement to ensure that the individual continues to meet the non-medical program requirements. This process is known as Redetermination. For more information about the SSA redetermination process, visit <https://www.ssa.gov/ssi/text-redets-ussi.htm>.

SSI Application

Applicants for SSI benefits can begin the process on-line at www.ssa.gov. Click on the link for SSI, and then complete the on-line disability report. Social Security needs both medical and non-medical information from the person applying. Most applicants also need to complete an in-person interview with Social Security.

- Call Social Security at 1-800-772-1213 to arrange an appointment at the local Social Security Field Office to complete the SSI application and interview
- To find the office nearest to the individual's home, visit <https://secure.ssa.gov/apps6z/FOLO/fo001.jsp>

Some applicants are now able to file the complete SSI application online if they meet certain requirements:

- Between ages of 18 and 65;
- Never married;
- Are not blind;
- Are a U.S. citizen residing in one of the fifty states, D.C., or Northern Mariana Islands;
- Haven't applied for or received SSI benefits in the past; and
- Are applying for SSDI at the same time as SSI claim.

For More Information about SSI

<https://www.ssa.gov/benefits/ssi/>

2) Medical Coverage

Objectives: Medical

- Review services available to Adults with I/DD
- Eligibility criteria for various Medicaid programs
- Understand other insurance options under ACA, private insurance, employment based insurance (own/parent's employment)
- Be aware of how Medicare and Medicaid integrate, especially around waiver services

Medicaid

In Illinois, Medicaid is used to pay for an array of services and supports for people with I/DD. These include services that are traditionally thought of as medical, such as doctor visits, hospital services and prescription medications. Medicaid is also used to pay for Long Term Services and Supports (LTSS) under the state's waiver authorities.

Medicaid is managed by two agencies in Illinois: the Illinois Department of Healthcare and Family Services (HFS) and the Illinois Department of Human Services (DHS). HFS is responsible for Medicaid policy, provider billing and reimbursement processes, and Manage Care Organizations' contracts. DHS is responsible for processing applications and communicating with families.

Medicaid Eligibility

There are two main programs through which eligibility can be established for adults with intellectual and developmental disabilities.

AABD Medicaid (Aid to the Aged, Blind and Disabled)

- Person enrolled in Medicare
- Income below \$1,041/month (100% FPL)
- Resources/assets below \$2000 for an individual

ACA Adult Medicaid

- Person not enrolled in Medicare, AND
- Income below \$1,436/month
- No asset limit
- Tax filing status determines who is included in household

According to the DDD, “one of the biggest misconceptions about DD waiver adults is that most agencies believe that adults should be placed on an AABD case if they have an approved waiver. This is simply not the case.”

There is also a Medicaid buy-in program for working persons with disabilities: [*Health Benefits for Workers with Disabilities*](#).

Aid to the Aged, Blind, Disabled (AABD) is an older program that gives cash and medical assistance to some low-income people who have disabilities or are senior citizens age 65 and older. There is an asset limit of \$2000 for a single person. (Some assets are not counted.)

Jill is 35 and has received Social Security Disability for three years. Her Medicare enrollment was effective last year. She receives \$1200 a month from Social Security. IDHS will enroll Jill into AABD Medicaid and she will have a spenddown.

ACA Adult Medicaid is a newer program, established by the Affordable Care Act, which takes a different approach to determining eligibility. A person does not need to have a disability or be elderly. Instead, the applicant must show that his or her income is below 138% of the Federal Poverty Level. There is no asset limit.

John is 35 and newly approved for Social Security disability. His Medicare will not begin for 2 years. John receives \$1200 a month from Social Security. IDHS will enroll John in ACA Adult Medicaid.

Families are sometimes concerned that their adult child(ren) will not be able to obtain Medicaid if they claim their adult child as a tax dependent. When the adult child has a disability and is claimed as a tax dependent, the state will first assess for ACA Adult program eligibility. If the tax filer’s income (often a parent) results in an ACA Adult denial for the person with I/DD, the DHS case worker should complete a second eligibility determination for the AABD program. Under AABD rules, the tax filer’s income will not count.

Spend-down (AABD)

If income or assets are above the limits, the person will have a "spend-down" if enrolled in the AABD program. A spend-down is similar to a deductible under an insurance policy. With a spend-down, he or she will be eligible for Medicaid coverage and will receive a medical card only after the monthly spend-down amount is met. The amount of the spend-down will change based on how much the income or assets exceeds the limits.

AABD Medicaid Calculation (Monthly)	
Earned Income (job)	\$500
SSDI Income	\$1,000
Total Monthly Income	\$1,500
Standard Deduction	-\$25
State Standard	-\$1,041
Spenddown Amount	\$434

An individual meets the spend-down amount by showing medical bills, expenses or receipts in the amount of the spend-down. This means that as soon as someone has medical bills in the amount of the spend-down, he or she has met the spend-down, even though the bills may not yet have been paid.

It is very important to keep copies of all medical bills, prescription receipts, and records of other medical expenses. When there are enough bills to meet spend-down, the individual must send copies of the bills to the local DHS office. The DHS caseworker will then process the bills so that the person can receive a medical card.

Individuals also have the option to enroll in the **Pay-In Spenddown** Program. The enrollment form for Pay-In Spenddown is included in the notices sent from DHS. Pay-in spend-down gives the person the option of paying the spend-down amount to HFS directly. This is a good option for persons with a lower monthly spenddown and those who may not have a lot of medical expenses, or persons who have other health coverage that helps pay for those expenses. The Pay-In Spenddown form must be completed, signed and returned if someone wants to be able to pay their Spenddown.

Example: Janet is enrolled in pay-in spend-down. Her spend-down is \$100. She needs a medical card for August because of a scheduled surgery, but she only has a \$50 medical bill to use toward her spend-down. To combine medical expenses and a pay-in payment, she gives a copy of the \$50 bill to the DHS caseworker and sends a \$50 payment to HFS to meet spend-down for August.

The types of expenses that can be used to meet the spend-down include:

- Physician and hospital services
- Medications
- Cost of travel to get medical care (when Medicaid is not directly paying for travel)
- Medicare and other medical insurance premiums, deductibles or other insurance co-payments
- Some dental expenses, many in-home care services, and over-the-counter medicines when prescribed by a physician
- Nursing home services
- Clinic services
- Medical supplies and equipment prescribed by your doctor
- Eyeglasses
- Insurance premiums, including Medicare premiums
- Speech, occupational and physical therapy
- Co-payments or deductibles you pay for medical care

The value of Home Based Services paid for by the State may also be used to meet Spenddown. Persons receiving a DD waiver must file a 2653 form annually to document the services. The 2653 form may be submitted and the State can approve Spenddown for a year at a time in these cases. Contact your ISC agency for assistance with this process. The form is available online at <https://www.illinois.gov/hfs/SiteCollectionDocuments/hfs2653.pdf>.

The bill for the medical services or medications purchased must be dated within the past six months. If the bill is older than 6 months, but is re-issued, and the person is still obligated to pay it, that may be used as well. A bill may not be used more than once to meet spend-down.

If you have not met your spend-down for three consecutive months, HFS will send you a notice stating that your case has been canceled. However, you may reapply for Medicaid when you have enough bills to meet the spend-down.

Disabled Adult Children and Spenddown

A Disabled Adult Child who received SSI at any time due to their disability, and their SSI ended because they started receiving new or increased Social Security benefits may continue to receive Medicaid. The new or increased Social Security benefits may be based on their own work history, or the more likely scenario is that they begin drawing Child Disability Benefits (auxiliary or survivors) from their parent's work history as was discussed in Section 1 of this guide. If their new Social Security Income puts them over the income limit for AABD Medicaid, the DHS caseworker is to approve the medical benefits as an "AABD Cash zero grant case." This

means that they should not have a Spenddown. The key is that they received SSI at some point and that SSI ended due to the conversion to other Social Security benefits. This policy is not always well known, even with DHS caseworkers. For reference, the DHS policy may be found in the Department's Cash, SNAP and Medical Manual online (PM 06-06-01: Disabled Adult Children) at <http://www.dhs.state.il.us/page.aspx?item=13834>.

Example: Sam has been receiving SSI of \$771. Sam's father recently retired and filed for his Social Security Retirement. Sam's father will be receiving a monthly retirement benefit of \$2,800/month. Social Security approved Child Disability Benefits (CDB) for Sam. Sam is told he will be able to receive DAC benefits of \$1,400/month. Sam's SSI will end since the CDB rate is a greater amount.

Even though Sam's income is above the current AABD income limit of \$1,041, he may continue to receive Medicaid with no Spenddown.

Health Benefits for Workers with Disabilities (HBWD) is a Medicaid Buy-In program. Working persons who have a disability may access Medicaid through this program. The HBWD program allows individuals to earn a higher income and maintain resources beyond the limits of the AABD program. These individuals will pay a monthly premium for their Medical card through this program. The premium amount is indexed to their income.

To qualify for the HBWD program, an individual:

- Must be at least 16 years of age and under age 65
- Must meet Social Security Administration definition of disability
- Must be employed or self-employed and paying payroll taxes
- Income below \$3,643/month (350% FPL)
- Countable assets of \$25,000 or less

Example: Bruce has Down Syndrome and works at his local grocery store. He earns about \$250/week and receives Survivor's benefits of \$1,000/month as his father recently passed away. Bruce has \$5,000 in savings.

Under the AABD Program: Bruce would have a monthly Income Spenddown of about \$1,017/month plus a \$3,000 Asset Spenddown to meet once a year.

Under HBWD Program: Bruce would pay a monthly premium of \$81/month for Medicaid coverage.

For more information about HBWD:

<https://www.illinois.gov/hfs/MedicalPrograms/hbwd/Pages/default.aspx>

HBWD Hotline 1-800-226-0768

Applying for Medicaid

It is recommended that individuals apply online. *ABE*, Application for Benefit Eligibility, is the online application for medical, food or cash assistance in the State of Illinois – abe.illinois.gov Applications may also be submitted by paper via mail/fax, over the phone or in-person at a local DHS office.

The benefit of applying online is that applicants receive an electronic application tracking number and have proof of application. An *ABE* User Guide and other resources about how to use the online application are available at www.dhs.state.il.us/abe.

Identity Proofing

When applying for benefits, the *ABE* system will launch the electronic ID proofing process to verify the applicant's identity. The system will show a screen that asks questions only the individual would know, such as past addresses, family member names and more. This ID proofing process is based on a person's credit history. You may not be able to complete the

You may still submit an application online even if you cannot complete the ID proofing process online or over the phone. Click [Verify Identity later] to proceed with the web application.

electronic ID proofing process if you do not have a credit history or if you do not know the answers to the questions.

Manage My Case

Manage My Case is an online system to manage benefits received from the State of Illinois. Families access Manage My Case through the abe.illinois.gov website. ID proofing must be completed to use *Manage My Case*. As of January 2019, there is a way to request manual State Identity Proofing for persons who cannot complete the electronic or online ID proofing process. The State Identity Proofing Request Form is available on the DHS webpage at <http://www.dhs.state.il.us/page.aspx?item=76721>.

The individual must have an ABE User Account before returning this form. Every section of the form must be completed or it will not be processed. Copies of the person's proof documents must be sent to the ID Proofing Unit. Page 3 of the form lists the types of documents that will be accepted. Persons may send a copy of one (1) document from Column A or two (2) documents from Column B to the ID Proofing Unit:

Illinois Department of Healthcare and Family Services
ATTN: ID Proofing Unit
P.O. Box 19122
Springfield, IL 62794-9122

It may take up to 6-8 weeks to hear back from the state. Once the State processes the request, they will mail a notice that says whether the request was approved or denied. If successful, individuals may log into ABE with the username provided on the Request form and enter their personal information to link the account to their case. The personal information to enter includes Date of Birth and Individual ID. If they do not know their Individual ID, they may enter a Social Security number instead. Once they link to their account, they will be able to use the Manage My Case part of ABE.

The State Identity Proofing Request is a new process. There are plans to allow for uploading the form and documents at time of the ABE application. As of March 2019, that process is not yet available. Individuals will also be able to request ID Proofing at local DHS offices. The State is currently pilot testing this process at several Family Community Resource Center offices and is not available statewide as of June 2019.

Redetermination

At a minimum, Medicaid coverage must be renewed once a year. This renewal process is known as redetermination. During redetermination, the State will review ongoing eligibility for Medicaid Benefit Enrollment.

Individuals receiving Medicaid will receive two notices when it is time for redetermination. This first notice informs the person that the redetermination date is approaching, and that the *Illinois Medical, Cash and SNAP Redetermination Notice* will arrive about two weeks later. The second mailing will contain that actual notice and redetermination form. The form will contain the person's name and date of birth. The form also contains a barcode in the upper right-hand corner. The steps for completing this process include:

- Complete the preprinted *Illinois Medical, Cash and SNAP Redetermination Notice*.
- Attach any verifications and/or documentation ("proofs") requested.
- Sign the form.
- Return the form and any proofs by the date listed on page 3, #11 of the form.

This form must be completed and returned even if there have not been any changes to the individual's household or income. If the form is not returned or it is returned late, the Medicaid coverage will be terminated. If the case is cancelled, individuals have 90 days to return the redetermination form and proofs and the case may be reinstated, with no gap in coverage. If more than 90 days have passed, a new application must be completed for Medicaid coverage.

For individuals receiving DD Waiver services, there is an additional Level of Care Redetermination ("Clinical"). The service coordinator (ISC) is responsible for conducting a level of care/Wavier eligibility redetermination for continuing eligibility of services. This can be done during the time of the annual review of the Personal Plan. However, it is critical that the ISC complete the clinical redetermination on or before its next due date, regardless of the timing of the Personal Plan process. Per the DHS Division of DDD, the clinical redetermination must never be allowed to expire or become out of date.

The ISC agency should assist persons enrolled in DD waivers with both Redetermination processes.

If there are questions about the redetermination process, or if a DD case was improperly cancelled at rede, contact:

dhs.dd.medirede@illinois.gov

More information about Medicaid Redetermination is available online from the DDD at <http://www.dhs.state.il.us/page.aspx?item=117939>.

Medicaid Managed Care

Illinois has shifted to a managed care model for most Medicaid programs. The goal of managed care is “to provide enhanced quality and improved outcomes, all while managing costs.” The Managed Care Plans are offered under two different programs. *Health Choice Illinois* is available for persons enrolled in ACA Adult or Family Health Plans. For dual eligible persons (Medicaid & Medicare), managed care is available through the *MMAI Program* (Medicaid-Medicare Alignment Initiative). There are also *MLTSS plans* (Managed Long Term Services and Supports) for persons receiving Home and Community Based Services through a waiver or persons needing nursing home care. ***However, persons enrolled in the three DD waivers do not enroll in MLTSS plans.*** Persons who have private health insurance or are enrolled in the Spenddown program are also exempt from enrolling in managed care plans.

In managed care, patients choose a health plan and a primary care provider. Patients must abide by the plans rules such as using the plan’s provider networks, obtaining referrals or prior authorizations for certain services. Each plan offers care coordination services. Care Coordinators assist patients in navigating the system and accessing the care they need. Patients should contact the health plan’s member services number and ask to be connected to a Care Coordinator if they do not have one.

To compare plans and to enroll in a plan, visit <https://enrollhfs.illinois.gov> or call 1-877-912-8880 (TTY: 1-866-565-8576).

More about Health Choice Illinois

Health Choice Illinois plans are offered statewide to individuals enrolled in ACA Adult or Family Health Plans (All Kids, Family Care). There are currently six companies managing *Health Choice Illinois* plans in Illinois, two of which operate in Cook County only:

- Blue Cross Community Health Plans
- CountyCare Health Plan (*Cook County only*)
- IlliniCare Health
- Meridian Health Plan
- Molina Healthcare
- NextLevel Health Partners (*Cook County only*)

Individuals who must enroll in a *Health Choice Illinois* plan will be notified and will receive information about the plans in their area. It is critical that they review the notices and respond in a timely fashion. If they do not pick a plan, the State will auto-assign them to a plan and a provider. Once that plan becomes effective, individuals have a 90-day switch period in which they can change plans once. After that initial 90-days, they will be locked into the plan for a year. They will not be able to change plans until their open enrollment period and will have to use the providers in their plans network.

When choosing a plan, it is important to confirm with any current providers which plans they accept. There are some providers who do not accept any of the *Health Choice Illinois* plans,

but accept fee-for-service (or traditional) Medicaid. Providers are able to enter into single case agreements with plans to accept a single patient. This sometimes occurs with providers who have treated a patient for many years. However, this is a business decision between the provider and the health plan. There is no guarantee nor is there a mandate for providers to do this. Providers also have the right to end contracts with a health plan. A provider may accept a particular health plan one year, but then drop out of the contract the following year. If that happens, an individual may have to change providers. Another option is to change health plans at their open enrollment.

If an individual has to change providers and in the middle of treatment, there is a process called continuity of care, or transition of care. Most plans have a 90-day transition period in which the patient may continue to see the current provider, as long as they are in an existing course of treatment for a covered service that is medically necessary. The provider has to agree to accept reimbursement from the new plan for this time frame. It allows time for the patient to continue receiving treatment while transitioning to a new provider. The health plan's Care Coordinator should assist with this process.

The health plans cover everything that fee-for-service Medicaid covers. Some plans offer extra benefits. More information is available at the enrollhfs.illinois.gov website.

More about MMAI plans

MMAI (Medicare-Medicaid Alignment Initiative) plans are available to seniors and persons with disabilities who are enrolled in both Medicare and Medicaid. This population is known as "dually eligible." The MMAI plans currently operating in Illinois are:

- Aetna Better Health Premier Plan
- Blue Cross Community MMAI
- Humana Health Plan
- IlliniCare Health
- Meridian Complete
- Molina Healthcare

MMAI plans are not available statewide. It currently operates in the Greater Chicago region and in Central Illinois. However, not all plans are available in all counties within those two regions. It is best to use the enrollhfs.illinois.gov website to explore which plans are available in a specific region.

NOTE: Individuals cannot enroll in MMAI plans if they receive developmental disability institutional services, or are enrolled in the Adults with Developmental Disabilities Home and Community Based Services waiver.

MMAI plans brings together all of a person's Medicare, Medicaid and prescription drug benefits into one health plan. The health plans offer Care Coordinators to help a person manage their health care. The same rules about provider networks apply to MMAI plans. However, a dually eligible person who enrolls in MMAI has the option to opt out of their health plan at any time. This is due to the fact that MMAI is a demonstration project between the State of Illinois and the Federal Center on Medicaid and Medicare Services (CMS).

For more information about MMAI, visit the Resource Center page on the Enroll HFS website at <https://enrollhfs.illinois.gov/resource-center> .

Age Options, the Area Agency on Aging for Cook County, provides information about MMAI on their website at http://www.ageoptions.org/services-programs_MedicareMedicaidAlignmentInitiativeConsumerMaterials.html

Medicare

Medicare is health coverage for seniors and persons with disabilities. Medicare is a federal program available to persons with the qualifying number of work credits. Seniors may receive Medicare at age 65. Persons with disabilities are eligible for Medicare after receiving Social Security Disability Insurance (SSDI) benefits for at least two years (24 months). Medicare is *not* available for persons who receive only Supplemental Security Income (SSI).

Adults with I/DD may qualify for SSDI and then Medicare on their own work history or a parent's work history. Children under age 18 cannot receive Medicare unless they are diagnosed with End Stage Renal Disease.

***Example:** Sam has been receiving Child Disability Benefits ever since his father retired two years ago. Because he is already receiving benefits from Social Security, they automatically enroll him in Medicare. He receives his Medicare card in the mail. He will not pay a monthly premium for Part A but his Part B premium of \$135.50/month will be deducted from his Social Security benefit.*

Medicare has various parts and costs associated with it.

- **Part A** provides coverage for hospital stays. Someone with sufficient work credits does not pay a monthly premium but there are deductibles and co-insurance costs when hospitalized.
- **Part B** provides coverage for outpatient services like doctor's visits or lab tests. There is a monthly premium for Part B. If someone is receiving SSDI, that premium will be deducted from their monthly benefit.
- **Part D** provides prescription coverage. Part D is administered by private health plans that are Medicare approved.

- **Medicare Advantage** plans combine Part A, B and usually D coverage into one managed care plan. Persons are restricted to the plans provider networks – meaning they must use providers that are contracted with their Medicare Advantage plan.
- **Medigap Plans (or Medicare Supplemental Plans)** offer additional coverage for persons enrolled in Part A, B and D. These plans may help with costs like deductibles for Part A or cover things not covered by the other Parts. These plans are administered by private health insurance plans and have an additional monthly premium.

Enrolling in Medicare

Social Security will automatically enroll individuals in Medicare if they are already receiving Social Security Retirement or Disability Insurance. They will be notified of the enrollment and receive a Medicare card in the mail 3 months before the 25th month of disability.

When newly enrolled in Medicare, the person needs to decide on a Medicare Prescription Drug Plan (Part D). They may also choose to sign up for a Medicare Advantage plan instead of using “Original Medicare” (Part A, B, and D). There are only certain times in which a person may choose the Part D plan or Medicare Advantage Plan. When someone first becomes eligible for Medicare – they have a 7-month window to sign up for these plans. That 7-month period is known as the Initial Enrollment Period. That period:

- Starts 3 months before the 25th month of getting Social Security or disability benefits
- Includes the 25th month of getting disability benefits
- Ends 3 months after the 25th month of getting disability benefits.

If someone neglects to choose a Part D plan at that time, then they can sign up during the annual Open Enrollment Period. In addition, if someone is unhappy with the plan they chose, they can change plans during this Open Enrollment Period as well. This period runs from October 15 – December 7 each year.

For more information about Medicare: <https://www.medicare.gov/>

Persons who are enrolled in both Medicaid and Medicare are known as “Dual Eligible.” For persons with both Medicaid and Medicare, Medicaid will always be the payer of last resort. This means that providers must bill Medicare first. Dual eligible persons may also get help from Medicaid to pay their Medicare premiums and in some cases, deductibles. This is offered through the Medicare Savings Program with the state. Individuals apply for the Medicare Savings Program in the same way as Medicaid applications. The Illinois Department of Human Services processes these applications.

Senior Health Insurance Program

SHIP Counselors are available to help individuals and families with decisions about Medicare. These SHIP Counselors are usually staff or volunteers with community based organizations. They have received training to help educate individuals so they may make an informed choice. To find a SHIP Counselor near you, contact the Illinois Department of Aging at 1-800-252-8966 or email AGING.SHIP@illinois.gov. Additional information is available on their website at <https://www2.illinois.gov/aging/ship/Pages/default.aspx>.

Health Insurance

Health insurance is available to individuals and families through a number of options. Some people are offered health insurance from their employers but others may privately pay for a health insurance plans. Employer plans are often referred to as “group policies.” Plans are referred to as individual policies if the person is buying the plan privately. The Patient Protection and Affordable Care Act (also known as the ACA or nicknamed “Obamacare”) introduced a number of consumer protections for individuals. Some of these protections apply to persons with I/DD.

One of the consumer protections that the ACA relates to dependent coverage. The ACA requires health insurance plans and issuers that offer dependent coverage to allow young adults to enroll in or remain enrolled in their parents’ plan until age 26. Some states have higher age requirements. Illinois does mandate that insurers cover children past age 26 if the child is disabled. However, the Illinois law does not apply to all insurance policies. The following types of plans are exempt from the law (meaning they do not have to cover disabled adult children):

- Individual or group health insurance policies or HMO contracts that do not otherwise include dependent coverage;
- Short-term travel, disability income, long-term care, accident only, or limited (including dental and vision) or specified disease policies;
- Business employer plans which are self-insured and non-public.
- Self-insured health and welfare plans, such as union plans.
- Insurance policies or trusts issued in other states, except for HMO contracts written outside of Illinois, if the HMO member is an Illinois resident and the HMO has established a provider network in Illinois.

Employer Coverage

An adult with I/DD may be able to access private health insurance through their own work or their parent’s coverage. Many companies offer group policies through an HMO or a PPO model. Some may also offer Health Savings Accounts or High Deductible Health Plans. It can be difficult to decide what plan will work best for an individual and family. The following table provides a comparison of some of the common features that plans may offer:

Feature	HMO	PPO	HDHP
<i>Provider Network</i>	Closed (In-Network only)	Open (in- and out-of-network)	Depends
<i>Referrals Required</i>	Yes	No	No
<i>Out of Network Coverage</i>	No	Yes	Some
<i>Low Premiums</i>	Yes	No	Yes
<i>Low Deductibles</i>	Yes	Some	No

When selecting an employer plan, it is important to review the Summary of Benefits Coverage, which will outline costs and types of services covered. This summary will also inform individuals of services are not covered with the plan. Employers generally offer an open enrollment period annually. This is the one time a year in which an employee can change plans. Sometimes an employee may have a qualifying life event that will allow for a Special Enrollment Period. Common life events include marriage, divorce, birth, death or loss of other coverage. Under most employer plans, an employee only has 30 days to report the life event and see if there is an opportunity to make a change or add a family member through a Special Enrollment Period.

Self-insured plans

Larger companies and unions may offer coverage through self-insured plans. Sometimes school districts and government agencies are self-insured. This means that the company can pay for their own health costs. These companies may use a major health insurance company to process the health bills of employees, but in essence it is the company that is paying for the health care. If a company is self-insured, the rules are different. State insurance laws do not apply to self-insured health plans. These plans are regulated by the Department of Labor. If there are questions about covered services or dependent coverage, consult the member handbook or contact the plan’s administrators.

COBRA

The Consolidated Omnibus Budget Reconciliation Act (COBRA) is a federal law which provides continuation of group health coverage that otherwise may have ended due to employment ending. COBRA applies to group health plans maintained by employers with 20 or more employees. COBRA applies to many of the group plans offered by employers, including self-insured plans. However, COBRA does not apply to small employer plans (under 20 employees), certain church-related plans, federal employee or military personnel plans, disability income plans, life insurance, or long term care coverage.

When employment ends, the employer will notify the employee if COBRA coverage is an option. Employees have up to 60 days after employment ends to enroll in COBRA. The employee will be responsible for the entire premium for the plan, including the share previously paid by the employer. This can be costly but for some consumers who may not have another source of health coverage, it is important to maintain continuity of care.

ACA Coverage

The Affordable Care Act (ACA) provided a number of consumer protections, offered a new way for individuals to purchase health insurance and included subsidies (financial help) to pay for health insurance. This coverage is offered through the ACA Marketplace, also sometimes referred to as “the Exchange.” The Marketplace is accessed online at www.healthcare.gov. The Marketplace is for individuals and families who do not have another source of health coverage. If someone is eligible for Medicaid or Medicare, or they have health coverage from an employer, then they will not be able to buy a plan through the ACA Marketplace.

Financial help to pay for monthly insurance premiums is available to individuals earning between 100% - 400% FPL (up to \$48,560/year for a single person in 2019).

The consumer protections provided under the ACA are of importance to persons with I/DD. Under these protections, health insurance companies are not allowed to:

- Impose lifetime limits for what they will pay for care
- Impose annual limits
- Deny coverage to children based on pre-existing conditions.

The ACA also mandates that qualified health plans offer a minimum level of coverage in ten categories of care, known as Essential Health Benefits. These categories are:

- Ambulatory patient services
- Emergency services
- Hospitalization
- Maternity and newborn care
- Mental health and substance use disorder services, including behavioral health treatment
- Prescription drugs
- Rehabilitative and habilitative services and devices
- Laboratory services
- Preventive and wellness services and chronic disease management

- Pediatric services, including oral and vision care.

For more information about the ACA:

- www.healthcare.gov
- <https://autisticadvocacy.org/wp-content/uploads/2013/09/ACA-ASAN-policy-brief.pdf>

Illinois Department of Insurance

The Illinois Department of Insurance regulates most group plans and ACA plans in Illinois. The Department has a number of resources for individuals and families on their website:

<https://insurance.illinois.gov/HealthInsurance/ConsumerHealth.html>

In addition, their Office of Consumer Health Insurance (OCHI) is available to educate consumers and can help individuals understand their coverage. OCHI can:

- Explain rights as a health care consumer;
- Answer questions about health insurance;
- Help individuals understand the coverage provisions of their specific health care plan; and
- Assist individuals when they have a problem or complaint.

OCHI cannot help with Medicaid or Medicare plans. Contact OCHI by calling 1-877-527-9341.

Federally Qualified Health Centers

Federally Qualified Health Centers (FQHCs) are community-based health care providers that receive federal funds to provide primary care services in underserved areas. Some FQHCs receive funding to serve special populations. These health centers are a part of the health care safety net, and may fill a gap in primary care when persons do not have other forms of health coverage. FQHCs often charge on a sliding fee scale.

To locate a health center, visit <https://findahealthcenter.hrsa.gov/>.

3) Waiver Services

Objectives: Waiver Programs

- Overview of various waiver programs and differences with general Medicaid coverage and DRS services
- Review the LIGAS consent decree and how this impacts waiver services
- Understand how to become a LIGAS member
- Overview of PUNS and understand the difference of PUNS and receipt of DRS services

Medicaid Waiver Introduction

Many families of young adults with disabilities first encounter Medicaid when they are applying for services funded through a Medicaid waiver. They may be confused about why they are being told to apply for Medicaid when what they.

Most people are familiar with the access to health care that Medicaid provides to individuals and families with limited income. However, Section 1915(c) of the Federal Social Security Act allows the state to operate Home and Community-Based Services (HCBS) within its Medicaid program if certain requirements are met.

WHAT IS A WAIVER?

Medicaid waivers "waive" one or more of the normal Medicaid rules in order to extend eligibility and/or services to people who would not otherwise get the services they need. Under the Home and Community-Based Services waiver, services are provided in the home to prevent someone from being institutionalized. States cannot spend more on waiver services than it would cost to provide care in a hospital, nursing facility, or intermediate care facility.

To be eligible for a HCBS waiver, persons must require an institutional level of care. Participants must be U.S. citizens or legal aliens, and Illinois residents. Each waiver has financial eligibility criteria that must be met. To learn more about the waivers, visit the Illinois Department of Healthcare and Family Services HCBS website at <https://www.illinois.gov/hfs/MedicalClients/HCBS/Pages/default.aspx>

Illinois manages nine 1915(c) waivers, operated by different state agencies. Services are provided in participants' homes, in non-residential settings outside their homes, and in residential services.

Three Home and Community Based Services (HCBS) waivers provide the services needed by people with intellectual and other disabilities. These three waivers are managed by the Division of Developmental Disabilities (DDD) within the Illinois Department of Human Services in conjunction with the Illinois Department of Healthcare and Family Services.

- Adults with Developmental Disabilities
- Supports Waiver for Children and Young Adults with Developmental Disabilities (Children's Support Waiver)
- Residential Supports for Children and Young Adults with Developmental Disabilities (Children's Residential Waiver)

Illinois Home and Community Based Services Waiver Programs

- **Adults with Developmental Disabilities**
- **Residential Services for Children and Young Adults with Developmental Disabilities**
- **Medically Fragile/Technology Dependent Children**
- **Persons who are Elderly**
- **Persons with Brain Injury (BI)**
- **Persons with Disabilities**
- **Persons with HIV or AIDS**
- **Supportive Living Facilities**
- **Support Waiver for Children and Young Adults with Developmental Disabilities**

Families access these waivers through PAS/ISC agencies (Preadmission Screening/Independent Service Coordination Agencies). These agencies are contracted with and receive funding from the State to conduct intake screening for persons needing services from the DDD and to coordinate and monitor services once the person is engaged. Staff from these agencies should be meeting with individuals on a regular basis. To find a PAS/ISC agency in your area, call the Developmental Disabilities Helpline at 1-888-DD-PLANS (1-888-337-5267).

Waivers are important for children because Medicaid typically counts the entire family's income when determining eligibility until a child turns 18. For children, the most common rule to be waived is the way income is calculated, meaning the waiver is based on the child's income instead of the family's income. Also, waivers often will provide services that private insurance does not cover, such as in-home care, private duty nursing, specialized therapies, and so forth. They may also offer additional services, such as respite, home/vehicle modifications, or training programs.

Ligas Consent Decree

The Ligas Consent Decree is the result of a 2005 lawsuit which was filed on behalf of individuals with developmental disabilities who were residing in private, State-funded facilities (Intermediate Care Facilities for Persons with Developmental Disabilities (ICF/DD)). A settlement in 2011 resulted in the Consent Decree. The Consent Decree mandates that placement be provided in Community-Based Services for those Ligas Members wanting community placement. The basis for this Decree is to provide choice to persons with disabilities about how and where they may receive services.

To qualify as a Ligas Class Member, an individual must be an adult (age 18+) in Illinois who has an intellectual disability or other developmental disability and who qualifies for Medicaid Waiver services:

- Who resides in private ICFs-DD with nine or more residents
- For who the State has a current record showing that the individual has requested community-based services or wants to live in a community-based setting
- Who reside in a family home and need community-based services or want to live in the community; and
- For who the State has a current record showing that the individual has requested community-based services or to live in the community.

To become a Ligas Class member, individuals should contact their PAS (Pre-Admission Screening Agency) to establish eligibility and become enrolled in the PUNS database.

For more information about the Ligas Consent Decree, visit the Illinois Department of Human Services website at <https://www.dhs.state.il.us/page.aspx?item=85190>.

Advocate organizations also have information available about the Ligas Consent Decree:

- <https://www.thearcofil.org/arc-and-the-ligas-consent-decree-what-you-need-to-know/>
- <https://www.ipaddunite.org/ligas-consent-decree-illinois>

5) Employment

Objectives:

- Know what types of supports Social Security allows regarding employment of persons with disabilities
- Understand the difference between income supports if receiving SSDI or SSI
- Be able to explain how to obtain a PASS agreement and how to effectively use to maximize income for education expenses
- Be aware of how to leverage DRS employment services and integrate with Social Security employment supports

People who have disabling conditions often want to work, and are often able to do certain types of work. But sometimes they fear that, if they try to work but are unable to continue, they may lose their benefits. Work supports vary depending on the type of benefit a person receives. If receiving disability benefits through the Social Security Administration, individuals may explore options in the Ticket to Work program. The State of Illinois also offers employment resources through the Supported Employment Program and Vocational Rehabilitation Program.

Ticket to Work

The Work Incentive Programs available to persons receiving disability benefits through Social Security are known as Ticket to Work (TTW). The Ticket to Work program is a free and voluntary program that encourages employment. Persons interested in the program should contact a designated Employment Network or by calling the Ticket Call Center at 1-866-YOURTICKET (1-866-968-7842) or TTY at 1-866-833-2967. A list of approved Employment Networks may be found online at www.ssa.gov/work/.

For persons receiving Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) benefits, it is critical that they promptly report any changes in work activity. They must report right away if they:

- Start or stop work;
- Already reported your work, but your duties, hours, or pay have changed;
- Start paying for expenses that you need for work due to your disability (known as Impairment Related Work Expenses/IRWEs).

WORK INCENTIVES FOR THE TWO FEDERAL PROGRAMS

Social Security Disability Insurance	Supplemental Security Income
Trial Work Period (9 months over a rolling 60 month period) in which you can earn whatever amount you are able and still keep your monthly benefit check	General Income Exclusion of \$20
Extended Period of Eligibility (36 months which starts immediately after the Trial Work Period ends)	Earned Income Exclusion of \$65 and then divide by 2 (2 for 1)
Expedited Reinstatement of Benefits (EXR) – If SSDI ended due to earnings from work, and work stops within 5 years of benefit end, SSA may be able to restart benefits for 6 months with no new application. SSA will conduct a medical review during this time to see if you remain disabled.	Expedited Reinstatement of Benefits (EXR) – If SSI Stops due to work and work ends stops within 5 years, SSA may be able to restart benefits with no new application. SSA will conduct a medical review during this time to see if you remain disabled.
Impairment Related Work Expenses (IRWE) – Social Security deducts from your income the cost of certain impairment-related items and services that you need to work. It does not matter if you also use these items and services for non-work activities (e.g. service animal, medication, medical devices, etc.)	Impairment Related Work Expenses (IRWE) – Social Security deducts from your income the cost of certain impairment-related items and services that you need to work. It does not matter if you also use these items and services for non-work activities (e.g. service animal, medication, medical devices, etc.)
Subsidy / Special Conditions When an employer pays the beneficiary for work which may not have the same value as non-disabled employee or when another entity, like VR, pays for Job Coach or other supports on the job. These can be applied only after the Trial Work Period, when working at SGA.	Plan for Achieving Self Support (PASS): Self-financed work incentive that requires an occupational goal tied to expenses which are paid for by setting aside SSDI, wages and/or resources
Unincurred Business Expenses/Unpaid Help – Self Employment Blind Work Expenses (BWE): taxes, union dues, work uniform, service animal expenses.	Blind Work Expenses (BWE): taxes, union dues, work uniform, service animal expenses.
Extended Medicare – 8 ½ years of free Part A after working at SGA	1619 a and b - Free Medicaid even after SSI check stops up to annual state threshold
Unsuccessful Work Attempt: is when earnings are over SGA but stopped, or produced earnings below the Substantial Gainful Activity level after 6 months or less	PESS Property Essential to Self-Support – Self Employment – allows a person to have resources that support the business and still be eligible for SSI/Medicaid
Ticket to Work – beneficiary can choose the Employment Services Provider (EN) with which to work	Ticket to Work – beneficiary can choose the Employment Services Provider (EN) with which to work

For more information: www.ssa.gov/work/

Supported Employment

Supported Employment is available to individuals with developmental disabilities through the Illinois Department of Human Services. Individuals with I/DD work and earn income in what is known as community-integrated work environments. These individuals will have interaction with coworkers without disabilities and also with the public. Individuals with I/DD who are working for a Supported Employment Program provide cannot receive funding from the waiver programs, except for Vocational Rehabilitation, without approval from the Division of Developmental Disabilities.

The Illinois Department of Human Services, Division of Developmental Disabilities recently updated their list for Supported Employment Providers for Intellectual Disability Services. The Division advises families to contact your ISC agency to discuss potential service providers and current service options.

To view the current list of Supported Employment Providers, visit <http://www.dhs.state.il.us/page.aspx?item=57222>

Vocational Rehabilitation

Vocational Rehabilitation (VR) services are provided through the Division of Rehabilitation Services (DRS) within the Illinois Department of Human Services. Persons who may receive those services are those with a physical, mental or developmental disability and the disability interferes with their ability to work, attend school or complete daily activities.

VR services are meant to help persons find and keep jobs. Individuals may receive additional training or supports that help them find work. Learn more at <http://www.dhs.state.il.us/page.aspx?item=29737>

For more information, contact DRS at 1-800-843-6154 or 800-447-6404 (TTY).

Other State Supports

Individuals who receive SSI or SSDI who want to work and who want to understand how work will impact benefits may contact the Benefits Planning program at Illinois Department of Human Services. For more information about Work Incentive Planning and Assistance, call 1-800-807-6962 (Voice) or 1-866-444-8013 (TTY). Information is also available at <http://www.dhs.state.il.us/page.aspx?item=29983>.

Adults who have a developmental disability who live in a residential setting or by themselves or with family may participate in Day Programs. Day Services are meant to include activities that help individuals develop skills, teach appropriate behavior and encourage independence. This service is accessed through the PUNS waiting list. Individuals should contact their ISC agency for more information.

6) Housing (or Residential Services)

Objectives:

- Understand housing options for adults with I/DD

There are a number of options through State funding for residential services for persons with I/DD, some of which are more restrictive than others. The options for community residential services include:

- Intermediate Care Facilities for Individuals with Developmental Disabilities (ICF-DDs)
- State Operated Developmental Centers (SODCs)
- Community Living Facilities (CLFs)
- Children’s Group Homes (CGH)
- Child Care Institutions (CCIs)
- Community Integrated Living Arrangements (CILAs)

More information about each of the residential services is available online in the IDHS [*Developmental Disabilities Program Manual*](#) (see Chapter 9-Resources).

Intermediate Care Facilities for I/DD (ICF-DDs)

ICF-DDs are residential facilities for individuals who have mental retardation or a related condition and who are in need of continuous habilitation services. Habilitation services are those supports and supervision that help individuals learn or improve skills to function in activities of daily living. These facilities do not typically accept individuals who need little supervision. The ICF-DD are often 16-bed facilities though some are larger. These facilities are regulated and licensed by the Illinois Department of Public Health.

State Operated Developmental Centers (SODCs)

SODCs are specialized ICF-DDs for persons with developmental disabilities who are unable to be served in a community setting due to intense behavioral and/or medical difficulties. According to McManus Consulting, “admissions to state operated centers are rare; the only individuals admitted are those with major behavioral challenges who cannot be served by the community.”

Community Living Facilities (CLFs)

CLFs provide services for adults age 18 and older with mild or moderate developmental disabilities. CLFs are licensed by the Illinois Department of Public Health and are not meant to be nursing or medical facilities. CLFs provide residents with skills training and supervision with

the intent to help them move to independent living. Residents are required to participate in day activities, such as job training, workshops or regular employment.

Children’s Group Homes (CGHs) and Child Care Institutions (CCIs).

These residential services are provided in a group home setting, licensed by the Illinois Department of Children and Family Services (DCFS). CGHs and CCIs are very similar in types of service and which children are eligible for placement. The primary difference is the number of beds at each type of setting. CGHs may serve no more than ten children, while CCIs are licensed to serve more than ten children.

CGHs and CCIs serve children with developmental disabilities who cannot reside in their home due to their level of needs. The application for services in CGHs must happen before the child is age 17 years and six months. The child must be enrolled in a school program and the need for residential placement identified in the child’s Individual Education Plan (IEP). The school district pays the cost of tuition in these settings. The child must be enrolled in the Children’s Residential Medicaid waiver if they will be placed in a CGH. The state prioritizes children with a DD who have an immediate, long-term need due to unexpected loss of current residence, physical or sexual abuse, neglect, incapable care-giver, or loss of a care-giver.

Community Integrated Living Arrangement (CILA)

A CILA is a flexible living arrangement for adults with a developmental disability. Services provided within CILAs include daily living and independent living skills training, money management, behavior management, community safety skills training and more. There are four options for CILAs:

- Group Homes
- Host Family Homes
- Intermittent Services
- Family Home Services.

Regardless of the type of CILA option you have, the services provided are overseen by a licensed CILA agencies. CILA Group Homes provide 24 hour supervision by trained staff. Group homes provide housing for up to eight individuals in a community setting.

Access to CILA is based on availability of funds. Individuals must be selected from the PUNS waiting list to access services through a CILA. Persons should work with their PAS/ISC Agencies access CILAs. It is the PAS/ISC Agencies job to help find living arrangements and help to make sure that you continue to receive the services that were provided in the ICF.

To learn more about CILAs, the State created a video which is available online at <http://www.dhs.state.il.us/page.aspx?item=75298>

Special Needs Resource Directories

There are a number of online resources available to families.

Title	Author/Organization	Web Address
<i>Developmental Disabilities Program Manual</i>	Illinois Department of Human Services	http://www.dhs.state.il.us/page.aspx?item=103254
<i>Consumer Handbook for Home-Based Services</i>	Illinois Department of Human Services, DDD	http://www.dhs.state.il.us/page.aspx?item=101181
<i>Multiple Fact Sheets and Youth Transition Resources</i>	Arc of Illinois – Family-to-Family Health Information Center	https://www.familyvoicesillinois.org/
<i>Transition by the Numbers</i>	DuPage County Transition Planning Committee	https://sites.google.com/view/dupage-tpc/transition-by-the-numbers
<i>NEXT STEPS: The Transition Series – The Guide to Future Planning</i>	The Parent Educational Advocacy Training Center	http://www.peatc.org/peatc.cgim?template=next_steps_series
<i>Alternative Housing Options for Individuals with Disabilities</i>	Community Partnership Project, Center for Independent Futures	Available on IPADD website at https://www.ipaddunite.org/ligas-consent-decree-illinois
<i>The Book: How to Navigate the Illinois Disability System</i>	Attorney Robert H. Farley, Jr.	http://farley1.com/
<i>Administering a Special Needs Trust: A Handbook for Trustees</i>	Rubin Law	https://www.rubinlaw.com/resources/sna-handbook-courtesy-of-rubin-law/

