



An Introduction to Developmental Disability Resources, Organizations, and Terms

For Family Members and Caregivers of Children of All Ages
with Disabilities and Professionals New to Developmental
Disability Services/Supports

May 2021



This presentation is intended to be introductory, and provides a broad overview of information important to families that include a loved one with an intellectual and/or developmental disability. We believe it could also be useful for new professionals to the field.

Sometimes, we learn about a disability at birth. Others don't get a diagnosis or know that there is a difference until later. Either way, upon learning that disability is part of life now, most have a mountain of information to digest!

We have put together this presentation to help **begin** that learning process. There will be new terminology and acronyms to learn each step of the way. Information on important services and funding will look different from one age to the next. There may be different eligibility criteria to understand and follow along the way.

There will be frustrating moments - including wait lists and barriers to needed services. But there will also be resources for information and help at each step along the way. You don't have to navigate alone! Let's get started!

Please know that the information shared here is current at the time recorded – but we are aware that links, policies, and information will change frequently!



The Arc.
Illinois

My EI person shared a couple groups near us that were focusing on inclusion. My EI person also shared valuable resources and contacts with us. This allowed us to participate in conferences and to talk to other parents - helping us to build a solid positive foundation for building a future in a new world.

An important lesson from my daughter (at age 4) - she let me know that I am her mother, not a teacher, a therapist, or a support staff person.

Resources Important to Families of Children/Youth

Early Intervention (EI)

To help children between the ages of birth to three with disabilities or delays, to learn and grow. Infants and toddlers are evaluated to see if there is a delay in:

- movement,
- learning,
- dealing with others,
- behavior, and/or
- self-help skills.
- [IDHS: Early Intervention Information \(state.il.us\)](https://www.idhs.state.il.us)

Child & Family Connections (CFC) - The entity that families need to call if they have a child with a disability diagnosis or worry that there may be a developmental delay.

They are the entry point for EI Services. You can find the CFC for your area by choosing “Early Intervention” as the Office Type at

<https://www.dhs.state.il.us/page.aspx?module=12>



Family Service Plan (IFSP) - the plan written to set goals and identify needs for children determined eligible for EI Services. If your child is evaluated or screened and is not eligible for services, but there are ongoing concerns – you can discuss possible options including therapy prescribed by the doctor. <https://www.dhs.state.il.us/page.aspx?item=96974>

Transition from EI to School - EI services end at age 3. Children who continue to have a need for services are transitioned from EI to the school system for services by age 3. The Illinois State Board of Education is the state agency responsible for special education services for children age 3 and older. [Early Childhood \(isbe.net\)](http://isbe.net)

EI Clearinghouse - The Illinois Early Intervention (EI) Clearinghouse identifies and collects research-based and best-practice early intervention information to share with families. They have a free Lending Library and EI Tip Sheets among their resources.

<https://eiclearinghouse.org/>



STARnet - Illinois STARnet provides a variety of opportunities for personal and professional growth for those who touch the lives of young children, ages birth through eight, with an emphasis on children with special needs. STARnet supports family-centered, researched and effective practices in early childhood education and care. <https://www.starnet.org/>

Illinois State Board of Education or ISBE – Illinois State Board of Education is the lead agency for public education in Illinois. There is information helpful to families on their website including the Parent Rights Guide for Special Education. ISBE also provides free IEP Facilitation Services. <https://www.isbe.net/Pages/Special-Education-Programs.aspx>



Special Education Services – Special education means specially designed instruction, at no cost to the parents, to meet the unique needs of a child with a disability . . . (<https://sites.ed.gov/idea/regs/b/a/300.39>) Some children may also need specialized therapies, equipment or other services and support to enable them to benefit from specialized approaches to instruction. These services and supports are also included in the child’s IEP.

Parent Rights Guide - from Illinois State Board of Education – Special education services are governed by federal and state laws. This family friendly document will be helpful in understanding the special education process and rules.

<https://www.isbe.net/Documents/Parent-Guide-Special-Ed-Aug20.pdf>



Individualized Education Plan (IEP) – “Each public-school child who receives special education and related services must have an Individualized Education Program (IEP). Each IEP must be designed for one student and must be a truly *individualized* document. The IEP creates an opportunity for teachers, parents, school administrators, related services personnel, and students (when appropriate) to work together to improve educational results for children with disabilities. The IEP is the cornerstone of a quality education for each child with a disability.”
(<https://www2.ed.gov/parents/needs/speced/iepguide/index.html>)

504 Plan - A 504 plan is intended for children with disabilities who do not need or qualify for special education but could benefit from accommodations and/or specialized help in school. These plans identify accommodations a child with a disability needs to fully participate in the classroom and sets up ways to help the child succeed. <https://www.verywellfamily.com/what-is-a-504-plan-3104706>



Transition – School to Adult and Post-Secondary - The transition process from school to adult services for youth begins officially at age 14 ½ and continues through age 21 as appropriate in Illinois. This is what folks think of most commonly when “Transition” is mentioned. ISBE resources on Transition:

[Indicator 13: Secondary Transition \(isbe.net\)](https://www.isbe.net/indicators/13)

** Illinois hosts a Statewide Transition Conference every year for youth in transition, families/caregivers, and professionals. This event provides current and best practice information on the transition from school to work, post-secondary education, and adult services for youth with disabilities.

<https://www.illinoistransitionconference.org/>



Parent Training & Information Centers or PTICs –Illinois has two PTICs. **The Family Resource Center on Disabilities** (www.frcd.org) covers the Chicago and Chicago suburban area. **Family Matters** (www.fmptic.org) covers the rest of Illinois to provide special education related information to families and professionals.

PTIC will

- assist parents of children with disabilities to be informed participants in the special education process.
- assist students with disabilities to understand their rights and responsibilities.
- supply information to teachers and other professionals who provide special education and related services to children with disabilities.



Community & Residential Services Authority (CRSA) – This agency is responsible for identifying and addressing barriers facing parents, professionals and providers when trying to get needed services and programs for individuals, through the age of 21, with a behavior disorder or a severe emotional disturbance and their family.

<https://www2.illinois.gov/sites/crsa/pages/default.aspx>

Family to Family Health Information Center – An Arc of IL Program and Illinois affiliate of a national organization called Family Voices, that serves families of children with special health care needs around health and health care/insurance information. Free monthly webinars, website information and phone support.

www.familyvoicesillinois.org



Illinois School for the Deaf, ISD - The mission of the Illinois School for the Deaf is to educate students who are deaf or hard of hearing to be responsible, self-supporting citizens. ISD is a program of IL DHS DRS. <http://www.illinoisdeaf.org/index.html>

Illinois School for Visually Impaired – ISVI - The Illinois School for the Visually Impaired (ISVI), established in 1849, is a residential/day school for students who are blind or visually impaired. ISVI is a program of IL DHS DRS. <https://www.dhs.state.il.us/page.aspx?item=87427>

Illinois Service Resource Center – The Illinois Service Resource Center provides behavior support for students who are deaf, hard of hearing, or visually impaired in Illinois. <https://www.isrc.us/>

Project Reach - Project Reach provides technical assistance, information, and training to address the early intervention, special education, related services, and transitional services needs of children with Deaf Blindness and enhance state capacity to improve services and outcomes for children and their families. <https://www.philiprockcenter.org/project-reach>



The Autism Program of Illinois (TAP) - The Autism Program of Illinois (TAP) Service Network is a collaboration of 4 universities and 11 organizations that together operate 20 centers across the state to provide services to children, families, educators, childcare providers, and medical professionals. <https://tap-illinois.org/>

UIC Division of Specialized Care for Children – A program that supports children with special health care needs such as cerebral palsy, epilepsy, hearing loss, technology-dependent children and their families through care coordination, evaluation, and more. They assist families of children with complex medical needs and those who qualify for the medically fragile and technology dependent waiver for children. <https://dsccl.uic.edu>



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I should have maximized student work experience and continued to have my child find/work or a job after he left school. We did not - and therefore, he is not eligible for Medicare coverage until one of his parents retires.

I realize the importance of having legal documents in place when child with I/DD turns 18. You need to plan ahead for your child and update the plan on an ongoing basis.

Resources Important to People with I/DD of All Ages



Centers for Independent Living - The Independent Living Movement started in the 1960s when students who used wheelchairs could not access college campuses. Every state now has a network of Centers for Independent Living. There are five core services they all are required to offer. The 5 Core Services offered by every CIL nationwide are:

- Advocacy, Self-Advocacy, Systems Advocacy
- Independent Living Skills
- Peer Support
- Information & Referral
- Transition Services

Transition from Institutional Setting to Community Living

Youth Transition Services

One can find a Center for Independent Living near them by going to www.incil.org or <https://www.ilru.org/projects/cil-net/cil-center-and-association-directory>



Equip for Equality – Equip for Equality is the Protection & Advocacy Agency for People with Disabilities in Illinois. From the Equip website: *“We are an independent agency and our primary goal is to protect the civil and human rights of people with disabilities”*. Equip for Equality provides trainings and information to people with disabilities, family members/caregivers, and professionals and also help with legal and systemic advocacy, and monitoring. www.equipforequality.org

Illinois Assistive Technology Program (IATP) - Provides expertise in assistive technology and accessible information technology to all Illinois residents of all ages with disabilities and/or health conditions including family members, friends, and caregivers, professional service providers in aging, community living, early childhood, education, employment, health care, veteran’s services, and other social services, Community, Social, and Youth Organizations, Large and small businesses, State Agencies and local governments
<https://iltech.org/>



Independent Service Coordination Agencies or ISCs - The ISC or Independent Service Coordination Agency is the “doorway” to funding for services from IL DHS Division of Developmental Disabilities. They maintain the PUNS waiting list and determine eligibility for that funding/services. [IDHS: Independent Service Coordination Manual \(state.il.us\)](https://www.idhs.gov/IDHS/IndependentServiceCoordinationManual/state.il.us)

Medicaid Waivers - What is a waiver? An agreement between Medicaid and a state that outlines how Medicaid will “waive” rules to allow for additional services to be funded. Services for people with intellectual and developmental disabilities and other disabilities are funded largely by Medicaid with state help.

<https://www.illinois.gov/hfs/MedicalClients/HCBS/Pages/default.aspx>



PUNS – PUNS is the name of the waiting list for funding for services through the IL DHS Division of Developmental Disabilities in Illinois.

https://www.illinoislifespan.org/wp-content/uploads/2020/08/PUNS-The-Basics-with-Categories-082020-Final-002.md_pdf

Respite – What is respite? From the Arch National Respite Network website: Respite is planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult.

In Illinois, there are grant programs funded through the IL DHS Division of Developmental Disabilities located statewide to provide respite. The Illinois Respite Coalition also has funding for Emergency Respite.

<http://www.illinoisrespitecoalition.org>



Supplemental Security Income (SSI) – A program administered by the Social Security Administration. SSI program provides monthly payments to adults and children with a disability or blindness and who have income and resources below specified amounts. SSI payments can also be made to people 65 and older without disabilities who meet the financial limits. <https://www.ssa.gov/ssi/>



Special Olympics – Illinois is the birthplace for Special Olympics. Soldier Field in Chicago hosted the first games in 1968. Special Olympics Illinois is a not-for-profit organization offering year-round training and competition in 18 sports for more than 23,000 athletes with intellectual disabilities and over 13,000 Young Athletes ages 2-7 with and without intellectual disabilities. <https://www.soill.org>

Special Recreation - A Special Recreation Association (SRA) is a cooperative formed by 2 or more park districts or municipalities who have joined together to provide recreation for their residents with disabilities. Contact your local Park District or neighboring districts if you do not have a local Park District for more information. <https://www.specialrecreation.org>



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Continued to explore, research, connect and grow relationships with groups/individuals having a disability focus on inclusion and community. Joining national groups provided a “bigger” picture on the issues families face and increased our knowledge of what was possible.

Talk to other parents and **get connected** to an agency and/or The Arc of IL, someone that can get you to resources.

Adult Intellectual/Developmental Disabilities Services Information



Adult Services through Medicaid Home and Community Based waiver funding to support adults with I/DD in the State of Illinois are NOT an entitlement, or “not automatic”. It’s important to know that services are not always available to everyone who needs them. Families must consider a back up plan.



Criteria for Adult Waiver Services: Health Coverage & Age

Must have **Medicaid** as a source of health insurance. A person can also have another form of insurance like parent employer based insurance or Medicare.

Age can be as young as 19 years old and/or when the individual exits the school system. Exiting can mean graduating and/or up to the last day of attendance before the last day of attendance before turning 22.



Criteria for Adult Services: Have an eligible Diagnosis/Condition

Developmental Disability (DD): A disability which is attributable to intellectual disability or a related condition. (Refer to the definitions of intellectual disability and related condition for further details.)

Intellectual Disability: Refers to significantly sub average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested before the age of 18 years. Significantly sub average is defined as an intelligence quotient (IQ) of 70 or below on standardized measures of intelligence. This upper limit could be extended upward depending on the reliability of the intelligence test used.



Criteria for Adult Services: Related Condition

A severe, chronic disability that meets all of the following conditions: It is attributable to Cerebral palsy or epilepsy or any other condition, other than mental illness, found to be closely related to intellectual disability because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of persons with intellectual disability persons, and requires treatment or services similar to those required for these persons.

- It is manifested before the individual reaches age 22.
- It is likely to continue indefinitely.

It results in substantial functional limitations in three or more of the following areas of major life activity:

- Self-care
- Language
- Learning
- Mobility
- Self-direction
- Capacity for independent living



Adult Services: Have A Source of Funding - a Medicaid Waiver

A Medicaid waiver is an agreement between Medicaid (federal) and a state that outlines how Medicaid will “waive” rules to allow for additional services to be funded. Services for people with intellectual and developmental disabilities and other disabilities are funded largely by Medicaid with state (IL) help from these two agencies.

<https://www.illinois.gov/hfs/MedicalClients/HCBS/Pages/default.aspx>

Division of Developmental Disabilities DDD (3 waivers)

<https://www.dhs.state.il.us/page.aspx?item=32253>

Department of Rehabilitation Services DRS (3 waivers)

<https://www.dhs.state.il.us/page.aspx?item=29727>



Division of Developmental Disabilities (DDD)

<https://www.dhs.state.il.us/page.aspx?item=32253>

Individual/family would

Complete the PUNS intake process with the local Independent Service Coordination Agency (ISC) and wait for selection for funding.

OR

If the person with a disability or the family is experiencing a crisis, contact the local Independent Service Coordination Agency (ISC) and complete or update the PUNS process. Crisis category information:

<https://www.dhs.state.il.us/page.aspx?item=131772>



PUNS is a database/list that registers individuals who want or need Developmental Disabilities (DDD) Waiver Services - <https://www.dhs.state.il.us/page.aspx?item=41131>

- Application is completed by individual and/or parent
- Must explain the current and future needs
- Must choose category: Planning (need is for the future) or Seeking Services (need services now)
- Must update information every year
- Recommended to get on list before age 18. The “clock” starts age 18 –
- The plan is . . . by 2025 no longer than a 5 year wait for those individuals in the Seeking Services category

There are 8 ISCs that cover the State of IL. Only ISCs can register a person/family on the PUNS list.

The route to Medicaid waiver funding: Home Based Support Services (HBSS) or Residential Services including Community Integrated Living Arrangement (CILA)



**IL DHS Division of Developmental Disabilities (DDD)
Home-Based Support Services or HBSS (Community) Waiver**
<https://www.dhs.state.il.us/page.aspx?item=81789>

The Home-Based DD Waiver option is linked to the annual SSI Monthly allotment of (2 x SSI for children (3 x SSI) for adults. This is calculated annually but there is no automatic annual increase. <https://www.ssa.gov/ssi/text-benefits-ussi.htm>

2021 Monthly allotment of \$2382/month (adult) and \$1588/month (child)

Commonly used services

- Personal Support/Respite
- Therapies (OT, PT, ST, ABA)
- Community Day Services aka Day Program, Developmental Training

There is a separate home/vehicle modification funding for which recipients can apply.



IL DHS DDD Home-Based Support Services or HBSS Important Roles/Terms

- Individual with IDD
- Personal Support Worker PSW
- Family/Guardian/Power of Attorney POA
- ISC Coordinator – ISSA (Individual Services and Support Advocacy)
- SDA - Self-Direction Assistance Agency (Optional)
- ACES\$ (Fiscal intermediary) offers payroll services
- Employer of Record signs off on PSW timesheets and Service Agreements - Can be a family member or the individual with IDD

<https://www.dhs.state.il.us/page.aspx?item=101181> DDD HBSS Consumer Handbook



DDD Residential Services:

Annual dollar value of services is based on individual need as well as the type of residential service

- Group Home or CILA (Community Integrated Living Arrangement) - up to 8 individuals in a home with 24/7 care
- Host Family/Shared Living (up to 2 individuals with a person/couple/family who act as 24/7 caregivers)
- Family Home (IDD service provider staff come into the house to provide care)
- Intermittent CILA (IDD service provider staff come in the home/apartment/wherever the person with IDD lives)
- Community Living Facility (CLF) up to 16 individuals with IDD

<http://www.illinoislifespan.org/wp-content/uploads/2020/02/ResidentialOptionsFinalAug2019.pdf>



Division of Rehabilitation Services (DRS)

- Apply in person at office or via online
- Must have Medicaid
- <https://www.dhs.state.il.us/page.aspx?item=29736>

****Note: DRS programs do not fund residential placement



Division of Rehabilitation Services (DRS) Vocational/Employment

Vocational Services – This includes assessment of job readiness skills, Job Coaching and Job Placement. This can be done directly with DRS counselor or a DRS funded partner agency. <https://www.dhs.state.il.us/page.aspx?item=29737>

- Supported Employment (job with supports that are faded out with time)
- Competitive Employment (regular job)

Division of Rehabilitation Services (DRS) Home Services

This program provides services to individuals with significant disabilities so that can stay at home and live as independently as possible. Available from birth through age 64. <https://www.dhs.state.il.us/page.aspx?item=29738> There is an assessment tool that determines physical and functional level of need. The assessment provides a “Determination of Need” score or DON.

This includes but not limited to

- Personal Assistance
- Electronic Emergency System
- Home delivered meals
- Adult Day Care
- Home Modifications (i.e. ramp, bathroom guardrails)
- Assistive Technology
- Respite



Other options for Adult Programming – Please note that these may not be available statewide.

- Park District and/or Special Recreation Cooperative: www.specialrecreation.org
- Private pay programs
- Post High School educational opportunities
- Life Skills Programs
- Community College Programs
- Specialty College
- College or University

Health care is probably the top issue nationally. Our son is pretty healthy. Looking into the future with a person who has Down Syndrome, we wanted to prepare him with the best health coverage. ***When he was about 12-14 I learned about Social Security credits and how the right amount would parlay him to Medicare.*** I learned this information in an informal conversation prior to a meeting, very casual circumstance. I am thankful for that off chance casual conversation with a Social Security employee.



Important to make sure estate planning is in place to take over when parents are no longer able to do it or when circumstances make a new strategy necessary.

Healthcare, Services and Medicaid in Illinois



Illinois Medicaid (Health Plan)

Medicaid is a jointly funded State and Federal government program that pays for medical assistance services for eligible children, parents and caretakers of children, pregnant women, persons who are disabled, blind or 65 years or older, those who were formerly in foster care services and adults aged 19-64 who are not receiving Medicare coverage and who are not the parent or caretaker relative of a minor child. Adults must be a resident of Illinois, a U.S. national, citizen, permanent resident or legal alien in need of healthcare/insurance assistance, whose financial situation is low income or very low income.

Medicaid eligibility is determined by a formula which uses the monthly income of an individual/family divided by the family size, for the most part.

<https://www.illinois.gov/hfs/MedicalClients/Pages/medicalprograms.aspx>



All Kids Program

Some families pay monthly premiums for the coverage but rates for middle-income families are much lower than they are on the private market. For example, in 2020, a family of 4 earning between \$51,432 and \$78,228 a year pays a \$30 monthly premium per child, and a \$10 co-pay per doctor visit. The income eligibility level is raised each year in January, using a method called FPL (Federal Poverty Level). <https://www.illinois.gov/hfs/MedicalPrograms/AllKids/Pages/about.aspx>

If you apply for Medicaid and are told that your family is “over income”, keep in mind that you can reapply if your circumstances change (for example, if your income goes down and/or your family size increases).

The *Moms and Babies* program for pregnant women covers healthcare for women while pregnant and for twelve months after the baby is born (up from 60 days), covering both outpatient care and inpatient hospital care, including delivery. Pregnant women receive immediate, temporary coverage for outpatient healthcare through Medicaid Presumptive Eligibility.

The *Family Care* program offers healthcare coverage to parents living with their children 18 years old or younger and covers relatives who are caring for children in place of their parents.



ACA Medicaid: After passage of the Affordable Care Act, Illinois expanded the Medicaid program to cover adults age 19-64 who are not the parent or caretaker relative of a minor child to include adults who are low income (138% of the federal poverty level). <https://abe.illinois.gov/abe/access/>

AABD Medicaid: The Aid to the Aged, Blind and Disabled (AABD) program offers healthcare to adults with very low income (100% of the federal poverty level). The IL Department of Human (DHS) together with the Illinois Department of Healthcare and Family Services (HFS) help individuals who had Medicaid as children transition to adult Medicaid upon turning 19. Such applications of an 18 year old turning 19 must be forwarded to hfs.aca@illinois.gov



Health Benefits for Workers with Disabilities (HBWD): A program providing health benefits for workers with disabilities ages 16 -64 with countable income of up to \$3404/month may qualify. Unlike other Medicaid programs, HBWD allows enrollees to have up to \$25,000 in assets. Depending on their income, enrollees pay a monthly premium to receive comprehensive healthcare coverage. HBWD is the Illinois Medicaid Buy-In program authorized under the federal Ticket to Work –Work Incentives Improvement Act. Eligibility for HBWD does not affect eligibility for personal care assistants through Dept. of Human Services Home and Community Based Services (HCBS) waivers.

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

Managed Care: In 2018 Healthcare and Family Services expanded their Managed Care program to cover all counties in Illinois. It's a program called HealthChoice Illinois with these care coordination companies: Aetna Better Health, Blue Cross Blue Shield, Meridian, Molina, Youthcare statewide for DCFS youth in care and former DCFS youth through Meridian, and County Care (Cook County residents only). <https://www.illinois.gov/hfs/MedicalClients/ManagedCare/Pages/default.aspx>



Home and Community Based Services (HCBS) Waivers (by Definition):

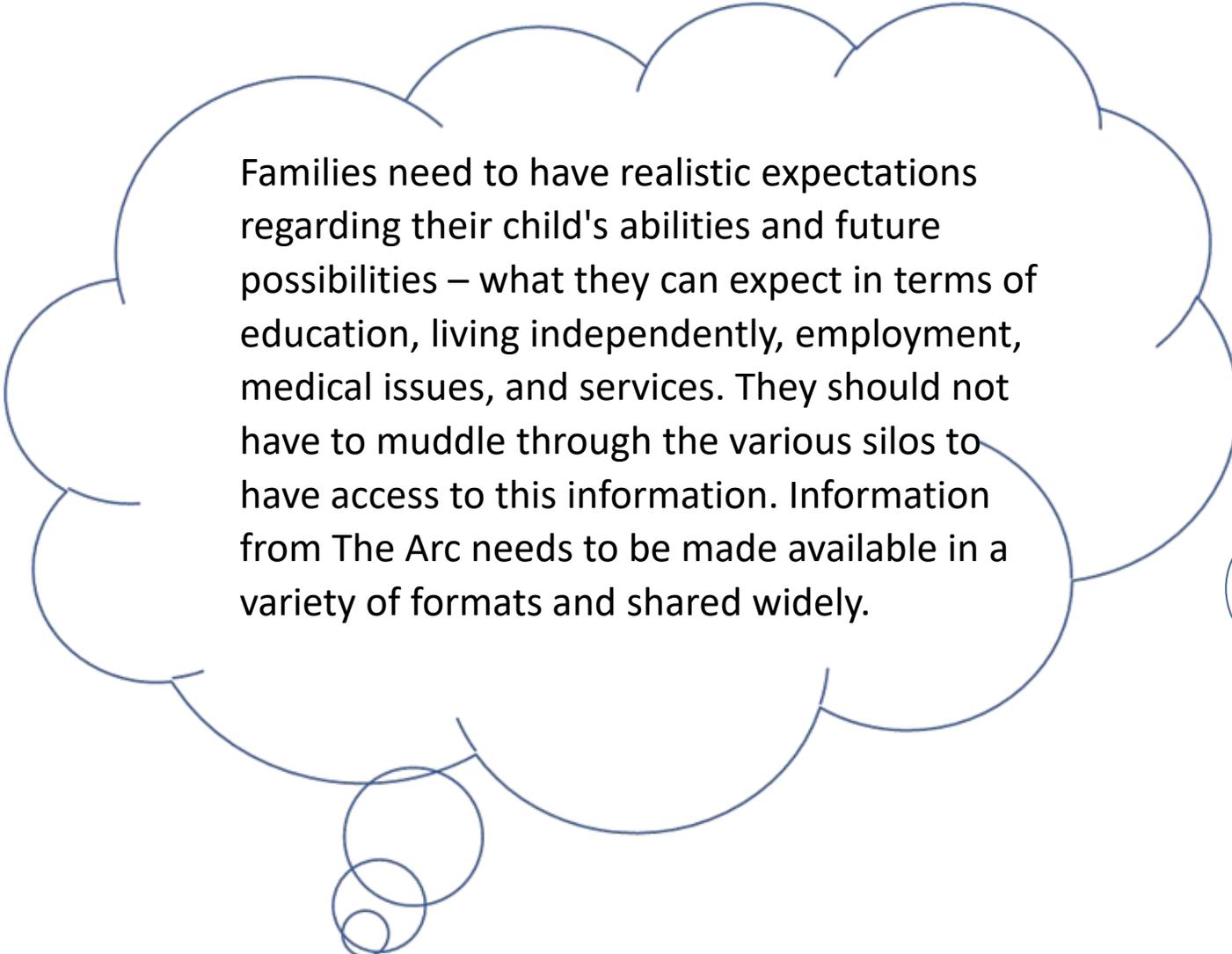
Medicaid Waivers help provide services to people who would otherwise be in a nursing home or hospital to receive long-term care in the community. Prior to 1991, the Federal Medicaid program paid for services only if a person lived in an institution. The approval of Federal Medicaid Waiver programs allowed states to provide services to consumers in their homes and in their communities. Each waiver is designed for individuals with similar needs and offers a different set of services. Individuals must be U.S. citizens or legal aliens and residents of the state of Illinois, meet Medicaid financial eligibility criteria as specified in each waiver; require an institutional level of care as specified in each waiver, service needs must be able to be provided in the waiver at a cost equal to or less than the cost for institutional care; and individuals must meet any other requirements, such as age or diagnosis requirements, specific to the waiver program.



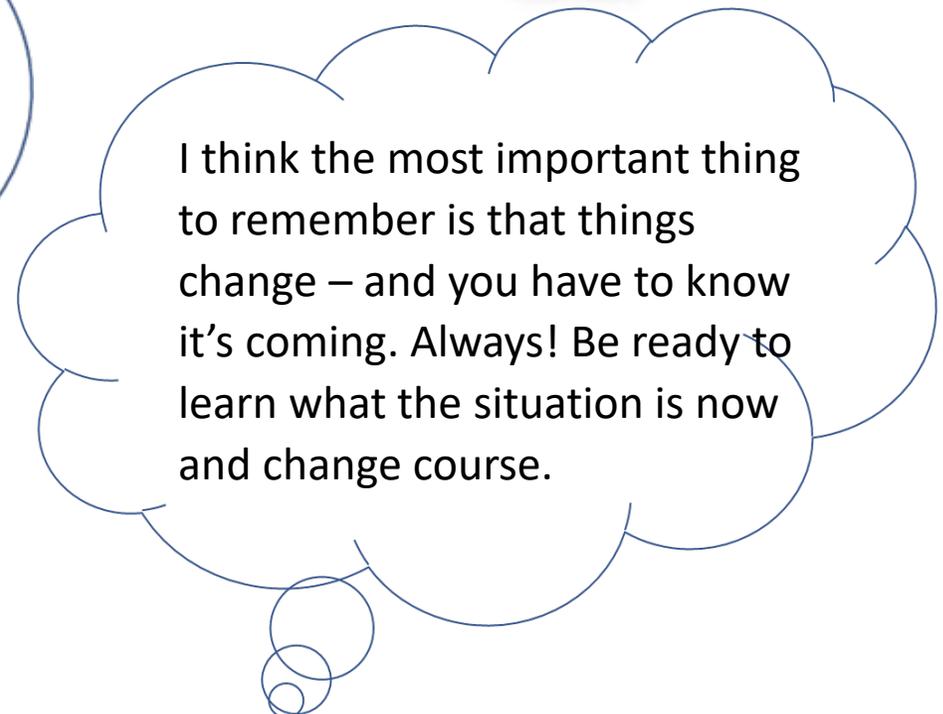
Home and Community Based Services (HCBS) Waivers in IL:

Illinois has nine HCBS waivers. Three of the waivers are for individuals with developmental disabilities (DD): the Children and Young Adults with DD Support Waiver, The Children and Young Adults Residential Waiver, and the Adults with DD Waiver. Additional waivers are the Medically Fragile, Technology Dependent Waiver, the Persons with Brain Injury Waiver, the Persons with Disabilities Waiver, Persons with HIV or AIDS, Persons who are Elderly and the Supportive Living Program. To learn more, see:

<https://www.illinois.gov/hfs/MedicalClients/HCBS/Pages/default.aspx>



Families need to have realistic expectations regarding their child's abilities and future possibilities – what they can expect in terms of education, living independently, employment, medical issues, and services. They should not have to muddle through the various silos to have access to this information. Information from The Arc needs to be made available in a variety of formats and shared widely.



I think the most important thing to remember is that things change – and you have to know it's coming. Always! Be ready to learn what the situation is now and change course.

Additional Important Terms, Programs, and Organizations



ABLE - ABLE “Achieving a Better Life Experience” accounts give people with disabilities and their families greater financial independence while preserving benefits. A high-quality, low-cost IL ABLE savings and investment account can be opened by an eligible individual, or Authorized Individual, at any time, no matter what state you live in. <https://illinoisable.com/>

Federally Qualified Health Centers, or FQHCs - Federally Qualified Health Centers are community-based health care providers that receive funds from the HRSA Health Center Program to provide primary care services in underserved areas. <https://findahealthcenter.hrsa.gov/>



Illinois Council on Developmental Disabilities, ICDD - ICDD works to promote the independence, productivity, integration, and inclusion of those with disabilities into the community, ensuring that those individuals with developmental disabilities have the same opportunities as others in the community. Moreover, the purpose of ICDD is to ensure that people with developmental disabilities participate and be included in everyday life, and be able to choose the services and supports that best fit their needs. To accomplish this, ICDD makes investments in people and organizations that serve people with disabilities throughout the State of Illinois.

<https://www2.illinois.gov/sites/icdd/Pages/default.aspx>

Illinois Department of Human Services, Division of Mental Health (DMH) - To ensure equitable access to a full continuum of preventive, supportive, and recovery-focused treatment resources that promote mental wellness for all people in Illinois. Provider of funding for mental health services in Illinois.

<https://www.dhs.state.il.us/page.aspx?item=29763>



Illinois Department of Human Services, Healthcare & Family Services (HFS) - The Illinois Department of Healthcare and Family Services (HFS) is responsible for providing healthcare coverage for adults and children who qualify for Medicaid, and for providing Child Support Services to help ensure that Illinois children receive financial support from both parents. The agency is organized into two major divisions, Medical Programs and Child Support Services. In addition, the Office of Inspector General is maintained within the agency, but functions as a separate, independent entity reporting directly to the governor's office. This agency used to be commonly known as Public Aid. <https://www.illinois.gov/hfs/Pages/default.aspx>



Illinois Partners in Policymaking – A training program funded by the Illinois Council on Developmental Disabilities, designed for parents of school age children with developmental disabilities and adults with disabilities. The Partners program was created by the Minnesota Governor’s Council on Developmental Disabilities more than 30 years ago, and has since been offered nationally and internationally.

<https://www2.illinois.gov/services/ICDD/icdd-training>

Illinois Self Advocacy Alliance - Self Advocacy is a very powerful tool. Politicians and policy makers will tune into the message of an individual with a disability to hear their stories first hand. The Self-Advocacy Alliance trains and prepares people on how to effectively share their stories. <http://selfadvocacyalliance.org/>



Social Security Disability Insurance (SSDI) – A program administered by the Social Security Administration. The Social Security Disability Insurance (SSDI) program pays benefits to you and certain family members if you are “insured,” meaning that you worked long enough – and recently enough - and paid Social Security taxes on your earnings. Additionally adults who are considered dependent adult children or DACs receive SSDI based upon the earnings of a disabled, deceased or retired parent.

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

Work Incentive Planning & Assistance (WIPA) - WIPA is a federally funded program created to help individuals receiving SSI/SSDI make informed choices about being employed. If you are working, have a job offer or ready to start employment, we will help you understand how working will affect your benefits.

<https://iltech.org/services/work-incentives-planning-and-assistance/>



Supporting Illinois Brothers & Sisters (SIBS) - Family support is essential. Siblings play an integral role in the lifespan of a brother/sister with disabilities. As the family grows it is important siblings are made aware of what will be expected of them. The Sibs network provides information as well as support for siblings in Illinois.

www.sibsnetwork.org and <https://www.facebook.com/siblingleadership>



The Arc of Illinois - Programs of The Arc of Illinois provide assistance to people with intellectual and/or developmental disabilities, family members, caregivers, and professionals in the field. Assistance is in the form of information and resources, legislative and policy advocacy, trainings and conferences, advocacy assistance, funding to attend conferences/trainings, and funding for assistive technology for those who qualify. <http://www.thearcofil.org>

Programs of The Arc of Illinois include:

- Arc Training Department
- Consumer Stipend Program
- Family to Family Health Information Center
- Family Support Network
- Family Transition Project
- Going Home Coalition
- Illinois Life Span Program
- Ligas Family Advocate Program



THANK YOU FOR YOUR TIME!

Information shared in this presentation was accurate at the time of posting. Please connect with the organizations/entities in which you have an interest to determine current status and details.