

HOW TO FIND YOUR WAY THROUGH THE DEVELOPMENTAL DISABILITY SYSTEM IN ILLINOIS

If you are reading this card, you are most likely trying to find information about service options for yourself or your family member. Each of these cards offers some necessary information as you get started, no matter where you live in Illinois.

This set of cards describes the basic steps in accessing Developmental Disability services in Illinois. Across the state, every county has an Independent Service Coordination (ISC) agency to help you coordinate all of these steps. (More information on the ISC appears on the next card.) Each of these cards covers a specific topic, and each:

- Describes what you can expect.
- Lets you know who you will talk with or who will be involved along the way.
- Provides local contact information for assistance.
- Lets you know how to prepare/what to have with you to make the most of each step.
- Provides a website where you can find more information



HOW TO FIND YOUR WAY THROUGH THE DEVELOPMENTAL DISABILITY SYSTEM IN ILLINOIS

WHO COULD BE INVOLVED?

Across Illinois, there are four types of agencies to help you:

- Independent Service Coordination – they will help you understand the rules, help you get services set up, advocate for you, and answer any questions you have.
- Service Providers – they will deliver the services you choose, for example support in getting or keeping a job, support with daily routines at home, finding ways to get around or to learn new things.
- Advocacy Agencies – these offer support to let you know your rights and can connect you with other families.
- Illinois Division of Developmental Disabilities Community Services – these are the offices of the State of Illinois who are responsible for making sure services are available, meet quality standards, and are monitored.

FOR MORE INFORMATION:

Contact your local Independent Service Coordination Agency:

Or Call the State of Illinois Division of Developmental Disabilities:
1-888-DDPLANS (1-888-337-5267)
TTY: 1-866-376-8446

Or Check us out on the web:
<http://www.dhs.state.il.us>
Choose *for Customers*, and then choose *Developmental Disabilities* from the list.

WHO IS AVAILABLE TO GUIDE US?

The role of Independent Service Coordination Agencies in Illinois

What Can You Expect from Independent Service Coordinators (ISC's)?

- They will explain each step of the process so that it is easy to understand.
- They will help you figure out where to go to find assistance that best matches your family member's needs.
- They will link you to programs and services that align with your family's preferences, gifts, talents and requirements., so that you can choose the best fit.
- They will get to know you and your family member so that you have someone you can turn to as more questions come up.
- They will guide and support you as you discover what services are available.



WHO IS AVAILABLE TO GUIDE US?

The role of Independent Service Coordination Agencies in Illinois

WHO ARE THE PEOPLE INVOLVED WITH INDEPENDENT SERVICE COORDINATION (ISC)?

- The ISC Agency serves the county where you live, and is responsible for assisting all people with a diagnosed Developmental Disability.
- The Independent Service Coordinator – ISC – will get to know your family member and you, and explain the steps to apply for services. The ISC makes sure you understand all of your options, and will help you complete forms, request documentation, sign approvals, and get the information you need.
- Qualified Intellectual Disability Professional – QIDP – (at the ISC) has the unique and extensive skills and knowledge needed to assist people with intellectual disabilities; particularly skilled in recognizing the indicators of an intellectual or developmental disability. Not all staff meet these standards, but each ISC agency has someone who does.
- Pre Admission Screening (PAS) agent – A PAS agent specializes in determining whether or not your family member meets the criteria to qualify for Developmental Disability services.

FOR MORE INFORMATION:

- Contact any of the following offices:
- Local ISC label here

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HOW DO WE GET STARTED OR SIGN UP?

Intake Procedures

WHAT TO EXPECT:

The first step to “sign-up” for Developmental Disability services is to provide information about your basic concerns, your contact information, and information from doctors, schools, or other agencies with whom you may already have talked. Most of this information can be collected over the phone, but you might be asked to meet at the local office or the Service Coordinator may meet you at your home.

You can expect:

- A staff member from the Independent Service Coordination office to talk with you and get to know you and your family member.
- To be asked questions about your family member’s medical history, educational services, therapies, where your family member currently lives, who else lives there, and if you have any worries about where your family member lives.
- To answer questions about other agencies you’ve talked to, where your family member went to high school and who suggested you call the ISC.
- To be asked questions about your concerns and why you have called or how the ISC can help you.
- To be asked questions about who helps you and your family member now, and who the most important relationships are in your family member’s life.



HOW DO WE GET STARTED OR SIGN UP?

Intake Procedures

WHO COULD BE INVOLVED?

- Independent Service Coordinator.
- You, your family member, and any other family or friends you want to meet with your ISC and talk about how things are going, and what you are concerned about.
- Your doctor's office, or the records office at the school your family member attended.
- A professional who first contacted the ISC on your behalf.
- Any other person or professional that you would like to be involved.

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HOW DO WE KNOW IF WE ARE ELIGIBLE FOR THESE SERVICES?

WHAT TO EXPECT:

- A staff member from your ISC agency will meet with you to explain all of the details, and ask questions about your family member's medical history and development since birth.
- They will explain Illinois' definition of Developmental Disability. It generally applies to people who have been identified as having a long term disability (needs help in three or more specific areas of daily life, along with other limitations) that was present prior to their 22nd birthday. This is true for any condition your doctor may have already diagnosed. Just having a diagnosis does not mean your family member is automatically eligible for services.
- You and your family member will be asked to provide permission (consent), to seek records from other agencies such as schools and/or doctors.
- How long it takes for the decision to be made will depend on how long it takes for the records to come from schools, doctors, and/or other agencies you've already seen, and whether or not those records are complete. In most situations, your family member will need to have had a psychological evaluation in the past, or one will need to be scheduled.
- Records needed include school records such as Individual Education Plans (IEP) or annual evaluations; doctor's reports, or reports from a psychologist.
- Once found eligible, your family member will have their eligibility re-determined each year.
- If you are not found to be eligible, the ISC will help you get connected to another agency that will best fit your family member's needs.



HOW DO WE KNOW IF WE ARE ELIGIBLE FOR THESE SERVICES?

WHAT TO BRING WITH YOU:

Some families have already met with other agencies and may have some of these records, others have not. If you bring the following records to your eligibility discussion, it will help us get an answer for you more quickly:

- Your family member's identification card, if one exists, and a Social Security Number, Medical Assistance Card or other identifying information cards for your family member.
- Any letters or forms that you have received from another agency which recommended you talk to a Developmental Disability agency.
- Your family member's primary care doctor's name, address, and phone number. Information from the most recent visit with your family member's primary care doctor, if you have it, and immunization records.
- Past test results from a psychologist or other doctor which provides IQ information.
- Your family member's High School Individual Education Plan (IEP) (even if it is several years old).
- Records from prior appointments with the Social Security Administration, or SSI/SSDI decisions.
- Medicaid or other Health Insurance Cards.

You do not need ALL of these- so if you don't have some of them, don't worry! Your ISC and PAS agent are here to help you figure out which ones you need!

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WILL I HAVE TO WAIT FOR SERVICES?

Prioritization of Urgency of Need for Services (PUNS) List

What is the PUNS?

- PUNS is a series of questions and a database used to gather and keep information about people with developmental disabilities who are potentially in need of services.

What is the PUNS Used For?

- Illinois uses PUNS to select individuals for services as funding becomes available and to plan for future needs.
- You and your family member may use PUNS to understand what category of need your family member is in, and how you relate to others waiting for services.
- The Independent Service Coordinator (ISC) uses PUNS to understand and plan for the person's needs, and to help provide you with guidance about what to do while you are waiting.

How is the Information Collected?

- Your family member, along with you and other members of your family, any caregivers or guardians, have a face-to-face meeting with an ISC to talk through the questions on the form.
- Based on the information provided during this meeting, the ISC will complete a "Prioritization of Urgency of Need for Services" (PUNS) form, and will identify your family member's need for services into one of these categories:
 - Emergency - someone who needs immediate service or support
 - Critical- someone who needs services within one year
 - Planning - someone who needs services in 1 to 5 years.

IT is really important that you update your information with your ISC EVERY YEAR, so that your family member's name and contact information is accurate when selections are made.



WILL I HAVE TO WAIT FOR SERVICES?

Prioritization of Urgency of Need for Services (PUNS) List

WHO COULD BE INVOLVED?

- You or your family member.
- A guardian, caregiver or someone your family member designates.
- Your Independent Service Coordinator.

WHEN DOES THE INFORMATION GET UPDATED?

- Every year, your ISC will call on the phone or send you a letter.
- If your family member's needs change at anytime, call your ISC and ask to update the PUNS.
- If your contact information (address/telephone phone number changes) BE SURE TO CALL YOUR ISC.
- If information about caregivers changes.

HOW WILL WE KNOW IF OUR FAMILY MEMBER IS SELECTED FOR SERVICES?

- If your family member is selected, you will receive a letter directly from the Department of Human Services announcing your selection.
- The letter will also tell you how to apply for services.

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Or Check us out on the web:

<http://www.dhs.state.il.us>

Choose *for Customers*, and then choose *Developmental Disabilities* from the list.

Or, go directly to the DHS site that explains the PUNS process here:

<http://www.dhs.state.il.us/page.aspx?item=47620>

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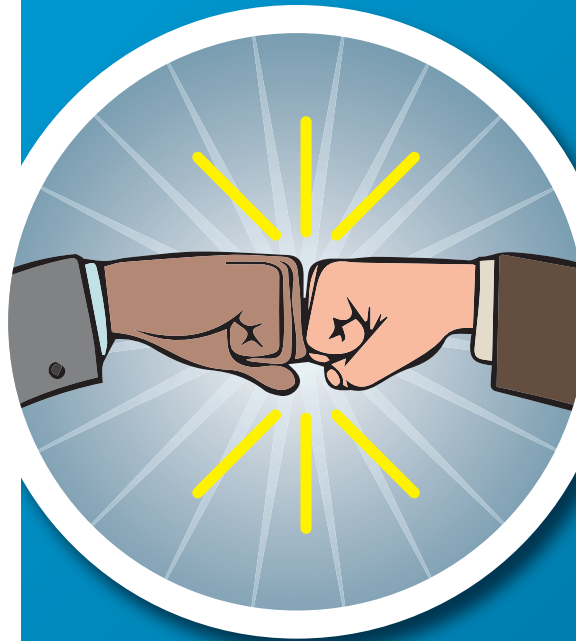
WHAT SHOULD WE DO WHILE WE WAIT?

(Building social networks)

You may need to wait for a period of time before support or services become available. While you are waiting, there are many things you can do to connect your family member to others. It may be very helpful for you to access other supports generally available in your community.

WHAT TO EXPECT:

- Connections or friendships with people who live nearby, or who know your family, create networks that can last a lifetime and can contribute to your family's overall well being.
- Staying in contact with friends from High School is important, so making arrangements to see each other routinely can lead to other opportunities.
- Community agencies are often looking for volunteers.
- Contact your local YMCA, community center or Family Resource Center for opportunities.
- Most counties have a parent support group – ask your ISC for their contact information, or call one of the many advocacy agencies in Illinois.
- The local employment office may have suggestions or opportunities to find hourly or part time work.
- You might want to contact the local Office of Vocational Rehabilitation to see if employment services are available.
- It might be several months or years until services begin – so you have time to set up connections and begin establishing friendships now.



WHAT SHOULD WE DO WHILE WE WAIT?

(Building social networks)

WHO COULD BE INVOLVED?

- Your family, your family member's friends, neighbors, and neighborhood groups
- Your church, synagogue, mosque, or other spiritual or faith-based groups
- Local community organizations like the YMCA, community centers, recreation centers, community colleges, family resource centers
- Employers or potential employers
- One of the Family Advocacy agencies in Illinois (ask your ISC for their information)
- Clubs and organizations that need volunteers for large events, such as Kiwanis, Lions, Rotary, and other community organizations that hold fund raising or awareness raising events.
- Special Olympics in your area is open to everyone and is a way to see people routinely.

FOR MORE INFORMATION:

Call 211 (United Way)

Contact your local Independent Service Coordination Agency:

Partners in Policy Making:

<http://cpfamilynetwork.org/mission/>

Special Olympics: <http://www.soill.org/>

Family Resource Center on Disabilities:

<https://frcd.org>

Family to Family

<http://familyvoicesillinois.org/>

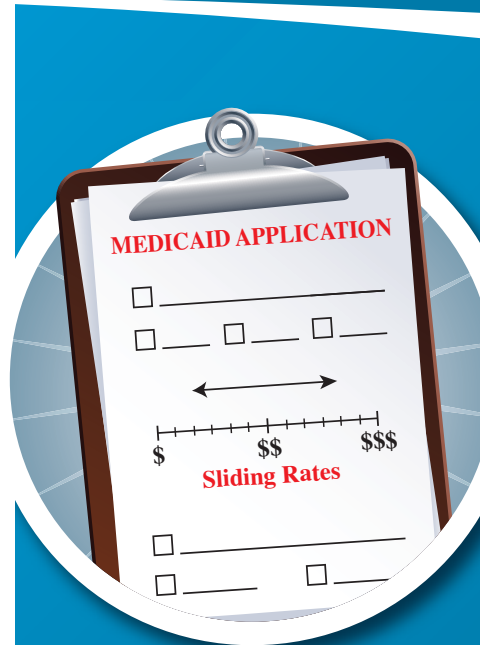
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UNDERSTANDING FUNDING

Medicaid Enrollment and Rate Setting

WHAT TO EXPECT:

- Most of the services available for people with intellectual or developmental disabilities are funded through the Illinois Medicaid system.
- When services become available, it is important that you know if you or your family member can sign up for Medical Assistance quickly. If you do this ahead of time, the whole process will move more quickly.
- For people over the age of 18, eligibility for Medical Assistance is based on the person's own income - not their parents' income. For children under 18 years old, eligibility is a combination of income and other conditions.
- Medical Assistance enrollment has some financial limitations - for example, each adult cannot have more than \$2,000 in assets; however, there are some exemptions that a benefits counselor will help you figure out. It's best to talk with someone about the details.
- If you are only applying for Medical Assistance (and not other benefits), you can apply online, or in-person at your local Family Community Resource Center. You will need the following information for the person applying: Proof of identity/photo ID; Full names and date of birth; Social Security numbers; Proof of where you or your family member lives; Information about all of the income everyone received; Amount of housing costs; and any utilities the person has paid.
- How much can be spent on services is often called "rate setting." Rates vary from one person to the next, based on each person's unique circumstances.
- The amount spent for services varies for each person and is usually based on the type and amount of need. Your family member will be asked to participate in an evaluation to determine what kind of service is needed and how much of that service before a rate can be identified.



UNDERSTANDING FUNDING

Medicaid Enrollment and Rate Setting

WHO COULD BE INVOLVED?

- Illinois Department of Human Services has a Family Community Resource Center in every county. Each local center employs a Benefits Counselor who will meet with you to determine your family member's assets and see if they meet the criteria for Medicaid eligibility.
- Your ISC will help you complete an evaluation called an ICAP Tool- Inventory for Client and Agency Planning- which will contribute to the determination of funding amounts.
- When services are available, the Illinois Department of Human Services, Division of Developmental Disabilities, will have Community Services Staff check the documents and records submitted to make sure they are all accurate and completely filled in, before submitting to the finance office for a decision on a rate.

FOR MORE INFORMATION:

**IDHS Bureau of Customer Inquiry and Assistance:
1-800-843-6154 TTY: 1-800-447-6404**

Apply for Medical Assistance here:
<https://abe.illinois.gov/abe/access/>

Contact your local Independent Service Coordination Agency:

The Family Community Resource Center in your local county.

If you are not sure where your local FCRC office is located, use the DHS Office Locator at:
<http://www.dhs.state.il.us/page.aspx?module=12>

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Or, visit our rate setting manual on our DHS website:
<https://www.dhs.state.il.us/page.aspx?item=16043>

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FIGURING OUT WHAT WILL HELP WHEN SERVICES ARE AVAILABLE.

(Individual Service Plan Development or Person Centered Planning)

What is an Individual Service Plan (ISP)?

- A written plan of services and supports for your family member.
- It includes what a person likes, wants and needs in their life.
- It includes the people and resources to help a person do the things they want to do in life.
- The Division of Developmental Disabilities uses the information from the plan, along with additional information, to determine amount of services for approval.

What makes Individual Plan Development Person-Centered?

- It is driven by the person-which means the person whose plan is being developed has the primary say in what is discussed, and in setting goals or outcomes for the coming year. .
- Includes people chosen by the person.
- The person is provided with necessary information and support to ensure they direct the process to the maximum extent possible.
- The plan is developed at least annually when it is convenient to the person.

What will the plan include?

- A complete picture of what is important to your family member.
- Your family member's strengths, preferences and needs.
- The supports that are, or will be, in place to help your family member meet or overcome any challenges they experience, such as alternative communication methods, visual supports, hearing devices, adaptive equipment, wheelchairs or special support to learn new skills.
- Goals and outcomes determined by your family member.
- Supports and services identified in the process.



FIGURING OUT WHAT WILL HELP WHEN SERVICES ARE AVAILABLE.

(Individual Service Plan Development or Person Centered Planning)

WHO COULD BE INVOLVED?

- Your family member who needs support.
- You, and other family members if they would like to be involved.
- People who know your family member best and can offer detailed information about his or her preferences, strengths, and needs.
- A guardian, surrogate, or advocate if desired or if needed for some people.
- The ISC.
- Chosen providers of service, after services have started.
- Other people who are important to the person and who they choose to invite.
- After the plan is written and submitted the Division of Developmental Disabilities will review it and use the information to make decisions on approval of services.

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WHO WILL PROVIDE THE SERVICES WE NEED?

(Choosing a Provider of Service)

How Do I Choose Qualified Providers?

- A qualified provider is one who has established they meet the licensing, quality and operational standards of Illinois.
- You ISC will provide information regarding potential qualified providers for needed services during the individual plan meeting.
- All qualified providers who are willing to offer services in your area, will be reviewed with you and your family member.
- You and your family member are responsible for choosing the agency you want to provide your support.
- Providers make decisions about their willingness to provide their services based on their ability to meet your family member's needs.
- Your ISC will make referrals to chosen providers promptly based on the selections you and your family member made.
- Providers are obligated to render services according to the specifications in the approved and authorized individual plan.



WHO WILL PROVIDE THE SERVICES WE NEED?

(Choosing a Provider of Service)

WHO COULD BE INVOLVED?

- You or your family member.
- A guardian, caregiver or someone you designate.
- Your Independent Service Coordinator will assist you in providing information about each qualified provider you will choose from.
- Talking with friends can also be helpful.
- Provider program managers who may provide you with details on their agency; you are encouraged to visit providers and ask questions prior to making your final selection.
- You can ask as many questions as you want; many families ask to see a specific location, or to meet direct support workers, before making a decision.

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HOW DO WE KNOW THINGS ARE GOING THE WAY THEY ARE SUPPOSED TO?

(Service Monitoring)

WHAT TO EXPECT:

- Your ISC will visit and interview your family member four times per year to ensure services are implemented as described in their Individual Service Plan. At least one of the visits will be at home, one will be where your family member spends most days, one will be focused on developing a service plan, and the fourth depends on your family member's living arrangements.
- Your ISC will contact you to set up the visit ahead of time and ask if you have specific issues or concerns you would like to discuss. Some visits may be unannounced.
- You are encouraged to be present for each visit; if the visit is in your own home, you must be present.
- Your ISC will ask some questions to ensure that your family member is satisfied, healthy and safe, and receiving all of the supports within the individual plan.
- Your ISC will take notes during this visit.
- If you or your family member are not satisfied with supports and services or if your family member's needs change, the ISC will arrange for a team meeting to discuss modifications in services as necessary to address needs.
- Visits may be unannounced and may be made more often than outlined above, if necessary, to resolve issues or in times of crisis.



HOW DO WE KNOW THINGS ARE GOING THE WAY THEY ARE SUPPOSED TO?

(Service Monitoring)

WHO COULD BE INVOLVED?

- Your ISC will check in with you and your family member. Visits will be no more than four months apart.
- A representative of the agency who provides services will check in with you and your family member more often.
- Depending on the services your family member receives, a Service Facilitator or other case manager may call monthly to ask about satisfaction.
- The State of Illinois Division of Developmental Disability (DD) services is responsible to monitor service providers.

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