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THE DEVELOPMENTAL DISABILITIES SYSTEM IN ILLINOIS

The Illinois Department of Human Services consists of five divisions:

- Div. of Developmental Disabilities
- Div. of Rehabilitation Services
- Div. of Mental Health
- Div. of Alcoholism and Substance Abuse
- Div. of Family & Community Services, which processes applications for Medicaid

Funding for services for individuals with intellectual and developmental disabilities is provided through the Div. of Developmental Disabilities, which has **seven regions** (formerly networks):

- North Suburban,
- South Suburban
- City of Chicago
- Northwest,
- North Central,
- Central
- Southern

Each region has one or two staff members. Their primary tasks are to receive applications for funding and to oversee provider agencies.

Services Available

The Division of Developmental Disabilities provides a variety of services--primarily:

- * For residential, the **Community Integrated Living Arrangement** (CILA), for adults over 18, and the **Children's Group Home**.
- * For in-home, the **Home-Based Services Program** for children and adults.
- * For day services, **Community Day Services** and **Supported Employment**.

Residential placement is also available through Intermediate Care Facilities for Individuals with Developmental Disabilities (ICFDDs). And the DHS Division of Rehabilitation Services provides Vocational Rehabilitation and Home Services to individuals with physical and/or mental disabilities. See below for details.

The Role of ISC Agencies

There are 17 Independent Service Coordination agencies (also known as Pre-Admission Screening (PAS) agencies) in the state, covering various geographical areas. Their two most important roles are:

- to handle **intake** for individuals seeking services from the Division of DD
- to **oversee delivery of services** once an individual obtains DDD funding.

All individuals who want services need to contact their local ISC agency. And once an individual is enrolled in a Medicaid Waiver program such as CILA or Home-Based Services, staff of the local ISC provide Individual Service and Support Advocacy (ISSA); they visit with individuals quarterly to assure that their needs are being properly met.

To get the name, address and phone number of the ISC agency serving your area, call 1-888-DDPLANS and enter your zipcode.

How to Obtain Services

Individuals with developmental disabilities and their families seeking services from DDD need to contact their PAS/ISC agency and register in the **Prioritization of Urgency of Need for Services** (PUNS) database. For information, search for PUNS on DHS website--dhs.state.il.us.

The way to obtain services is by being selected through PUNS (except in crisis situations).

1. Register in PUNS through the ISC. Individuals most in need of services, as determined by PAS, are given priority for selection.
2. As funds become available, DDD periodically selects names from PUNS. In the past few years, several thousand adults have been selected as the Department complies with the **Ligas** consent decree (see below). **No children are being selected at this time.**
3. Individuals and families are notified by mail when their names are selected.
4. ISC then screens the individuals to determine that they are enrolled in the federal Medicaid program and that they have a developmental disability. See Eligibility below.
5. ISC will assist the individuals in identifying a provider agency that can serve them, and the provider and PAS will submit an application to the region office.
6. The application packet is then forwarded to the Rates Unit, which will issue an award letter authorizing services. CILA rates are determined based on the person's needs.

In **crisis** situations—that is, in the case of "**imminent risk**" of abuse, neglect or **homelessness**—ISC may request immediate funding by taking the following steps:

1. Establishing eligibility.
2. Assisting the individual in identifying a provider.
3. Submitting a request for crisis funding.
4. Such requests are reviewed weekly by a committee consisting of the staff of the seven regions. For crisis criteria, go to PUNS page on website.
5. If approved, an award letter is issued.. If not approved, individual may appeal to Dept. of Healthcare and Family Services.

Eligibility

To qualify for services from the Division of Developmental Disabilities, an individual must:

- * Be found **eligible for the federal Medicaid program**. Apply at your local DHS office.
- * Be found by the PAS/ISC agency to have a **developmental disability**.

Developmental disability means:

An **Intellectual Disability** (also known as Mental Retardation)

- * Evaluation by a licensed clinical psychologist
- * Generally an IQ of 70 or below
- * Onset before the age of 18
- * Significant deficits in 3 of 6 life areas:
 - self-care
 - language
 - learning
 - mobility
 - self-direction
 - capacity for independent living

OR

A related condition: Cerebral palsy, epilepsy, autism or another condition **resulting in impairment of intellectual functioning or adaptive behavior similar to ID/MR**

- * Evaluation by a physician (or, in the case of autism, by a psychiatrist)
- * Onset before the age of 22
- * Deficits in 3 life areas

If an ISC agency finds an individual ineligible, he/she may appeal to the Division of DD. If the division finds an individual ineligible, he/she may appeal the finding to the Dept. of Healthcare and Family Services.

Residential Services

1. **Community Integrated Living Arrangement (CILA)**:

* **24-hour services:**

* **24-hour Shift-staff CILA**—a group home in the community housing up to 8 individuals, staffed by workers working in 8-hour shifts.

* **Host family CILA**—A 24-hour CILA in which two individuals live with a caregiver. Only a few agencies provide Host Family. There are two types of Host Family:

In the **Traditional Host family** model, it is the caregiver’s own home.

In the **Shared Living host family** model, the agency obtains a home and hires a roommate to live there and support the individuals

* **Less than 24-hour services:**

- **Intermittent CILA**—individuals can live on their own or with roommates and typically receive 15 hours per week of in-home services from a provider agency (or more hours if need is documented).
- **Family CILA**—an individual lives with his/her family. Family members are the primary caregivers, and the individual typically receives 15 hours per week of in-home services from a provider agency (or more if needed).

2. **Community Living Facility**: Usually a 12-16 bed building containing individual apartments, with a caregiver on site. Licensed by Dept. of Public Health. Admission not subject to PUNS selection. Only a few agencies provide this.

3. **Children’s Group Homes**: Admission restricted to cases that meet the crisis criteria. DDD often requires that families try in-home services first before seeking residential services.

4. **State Operated Developmental Centers**: There are currently seven in the state. An effort is under way to downsize these facilities by arranging for individuals to move to the community. The Jacksonville center was closed in 2012. There are no closures currently planned.

Admissions to state operated centers are rare; the only individuals admitted are those with major behavioral challenges who cannot be served in the community.

5. **Residential Respite**: Individuals may be placed in a facility for a short period to provide respite to caregiver.

In-home Services

1. **Home-Based Services**: Allows individuals living with family (or independently, in the case of adults) to obtain services. The individuals and families can choose from an array of services to determine which ones fit their needs. Prior to 2017, participants were required to select a Service Facilitation agency which would assist them in identifying providers of the services. This is now optional, although most participants have opted to continue getting the assistance, now known as Self-Direction Assistance.

Adults are allotted **\$2,250** per month in services; children and young adults in Special Education are allotted **\$1,500**. To use the program . . .

--Families may contract with provider agencies for a day program or personal support services,
--or they may hire members of the community, such as neighbors or relatives, to provide personal support,
--or parents of adults may designate themselves as the personal support worker.

Adults must be enrolled in the Medicaid program; children who are approved for the program are automatically enrolled in Medicaid regardless of parent income. Individuals may also apply for payment for **adaptive equipment and home and vehicle modification** totaling \$15,000 over a five-year period.

2. **In-home Respite**: A worker comes into the home to provide respite to family, usually 15 hours per month. A list of respite agencies can be obtained from the ISC; a family can then apply directly to the agency.

Day Services

There are two types:

--**Community Day Services** (formerly Developmental Training): Individuals attend a program approximately five hours per day, five days per week, and receive assistance in obtaining skills for independent living or perform work tasks in a workshop.

--**Supported Employment**: Individuals work in community with aid from a job coach. Available to individuals with higher capacity.

All persons in CILA are automatically entitled to Community Day Services. Persons in Home-Based can choose to spend some of their funds to attend a day program.

Previously, persons could be enrolled in Day Program Only. Some of those individuals are still in that category, but any new people seeking day services must apply for Home-Based.

Ligas Consent Decree

A class action lawsuit was filed by Equip for Equality and other organizations in 2005 on behalf of Stanley Ligas and other individuals living in Intermediate Care Facilities for Individuals with Developmental Disabilities who wanted to move to CILAs. The State agreed in 2011 to settle the suit through a consent decree. The decree had two parts:

-- It guaranteed that, over a six-year period, all persons in **ICFDDs** who wished to move out into CILAs (or home-based services) could do so.

--It guaranteed that, over six years, the State would provide CILA or home-based services to **3,000 adults living at home**; this was in addition to the individuals who met the Division's crisis criteria. (Note: The consent decree applies only to adults, not children.)

Several thousand adults have been selected from the PUNS database to receive services as a result of the decree. Half were selected for CILA and half for home-based; those offered CILA may opt for home-based instead. According to the Ligas implementation plan, in order to be selected for CILA funding a person must either:

- have a caregiver 75 or older,
- or be classified by their ISC agency as "emergency" (needing services immediately),
- or be classified as "critical" (needing services within a year).

Of those granted home-based funding,

- 40% are individuals identified as being emergency or critical,
- 30% are individuals who have left school in the last five years,
- and 30% have caregivers 60 or older.

Within those categories, persons are chosen based on how long they've been on the database.

The six-year period referred to above ended in June, 2017. After that, the decree requires the State to continue to select people "at a reasonable pace". Lawyers for the State and the plaintiffs are in the process of negotiating what that will be.

The decree is scheduled to end in 2020 but plaintiffs are likely to ask that it be extended.

In August 2017, the judge declared the State out of compliance with the decree, largely because of inadequate funding, and ordered them to come up with a plan. They submitted a plan in April 2018 but the judge rejected it and directed the parties to continue negotiating.

Other Services

1. Residential placement is also available through **Intermediate Care Facilities for Individuals with Developmental Disabilities** (ICFDDs). Many of these are 16-bed facilities; some are much larger. They are licensed and regulated by the Dept. of Public Health.

No approval by DDD is needed for admission; admission is arranged by the local Pre-Admission Screening/Independent Service Coordination (PAS/ISC) agency. Admission to an ICFDD is a **federal entitlement**, meaning that if an individual is eligible and the facility agrees to serve the individual, he/she is automatically entitled to funding.

Generally, ICFDDs do not accept individuals with DD who are relatively high functioning. A similar facility for children is called a Skilled Nursing Facility/Pediatric (SNF/Ped).

2. The DHS **Division of Rehabilitation Services** provides **Vocational Rehabilitation** (similar to Supported Employment) and **Home Services** (somewhat similar to the Home-Based program) to individuals with physical and/or mental disabilities. For information go to dhs.state.il.us, Div. of Rehabilitation Services, Program Highlights.

Some CILA residents or Home-Based participants are able to enroll in VR instead of participating in the Division of DD's supported employment program.

(For official information, please contact the Division. The information provided in this document is based on the knowledge of Ed McManus, former North Suburban Network Facilitator.)

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