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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 (North Cook, Lake, DuPage, McHenry, Kane and Kendall counties)

South Suburban (South & West Cook, Will, Grundy and Kankakee counties)

City of Chicago

and four downstate regions: Northwest, North Central, Central and 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.

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 PAS/ISC Agencies**

There are 18 Pre-Admission Screening/Independent Service Coordination (PAS/ISC) 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 PAS agency. And once an individual is enrolled in a Medicaid Waiver program such as CILA or Home-Based Services, staff of the local PAS 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 PAS 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 individuals obtain services is by being selected through PUNS (except in crisis situations). Here's how it works:

1. Register in PUNS through PAS.
2. As funds become available, DDD periodically selects names from PUNS. The PUNS selection process was announced in January 2008. In its first four years, approximately 900 children and adults were selected for services. Since February 2012, more than 4,300 adults have been selected as the Department complies with the **Ligas** consent decree (see below). **No children are being selected at this time** because of lack of funds.
3. Individuals and families are notified by mail when their names are selected, and they are instructed to contact PAS.

4. PAS will screen the individuals to determine that they are enrolled in the federal Medicaid program and that they have a developmental disability. See Eligibility below.
5. PAS 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. In the case of CILA, an individual rate is determined based on the person's needs.

In **crisis** situations—that is, in the case of **"imminent risk" of abuse, neglect or homelessness**—PAS 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** and to require "active treatment" for the 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

Active treatment means a program for the acquisition of behaviors to enable the individual to function more independently.

If a PAS 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 CILA**—a group home in the community housing up to 8 individuals.
- \* **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** model, it is the caregiver’s own home.

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

\* **Intermittent CILA**—individuals can live on their own or with roommates and receive 15 hours per week of in-home services from a provider agency.

\* **Family CILA**—an individual lives with his/her family. Family members are the primary caregivers, and the individual receives 15 hours per week of in-home services from a provider agency.

. \* All individuals enrolled in CILA are authorized for day services. There are two types:

--**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.

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. Governor Quinn in 2011 announced plans to close a total of four centers--the Jacksonville center has now closed. The Murray center in Centralia was in the process of closing but it was delayed by a lawsuit. The Rauner administration has stated that 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, and a service facilitation agency will assist them in identifying providers of the services.

Adults are allotted **\$2,199** per month in services; children and young adults in Special Education are allotted **\$1,466**. To use the program . . .

--Families may contract with provider agencies to provide a day program or personal support services,

--or they may hire 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 PAS; a family can then apply directly to the agency.

### **Ligas Consent Decree**

A class action lawsuit was filed by Equip for Equality and several 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 2008 to settle the suit through a consent decree, but many ICFDDs and guardians of individuals living in ICFDDs objected, and the federal court rejected the proposed decree. The plaintiffs and the State then proposed an amended decree, and the court signed it in June 2011.

The decree has two parts:

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

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

Since February 2012, more than 4,300 adults have been selected from the PUNS database to receive services. Half were for CILA and half for home-based. 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 PAS 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 had left school in the last five years,
- and 30% have caregivers 60 or older.

Within those categories, persons are selected based on how long they had been registered on the database.

### **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** to individuals with physical and/or mental disabilities. For information go to [dhs.state.il.us](http://dhs.state.il.us), Div. of Rehabilitation Services, Program Highlights.

(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.)

June 2015