

State of Illinois

Department of Human Services

**Institutional Services for Children
with Developmental Disabilities, Severe Mental Illness
and Severe Emotional Disorders**

Seventh Bi-Annual Report

March 2020

As Required by Public Act 095-0622

Table of Contents

Section	Page
Introduction	3
Overview	3
Current Status of Children in Institutional Settings	4
Community Alternatives	5
Summary of Comparison of Costs	7
Conclusion	9

Introduction

Public Act 095-0622 directs the Illinois Department of Human Services on or before March 1, 2020 to submit:

...a report to the Governor and the General Assembly regarding the extent to which children with developmental disabilities, severe mental illness, severe emotional disorders, or more than one of these disabilities, and who are currently being provided services in an institution, could otherwise be served in less-restrictive community or home-based settings for the same or for a lower cost. The Department shall submit bi-annual updated reports to the Governor and the General Assembly no later than March 1 of every even-numbered year.

The Department of Human Services (DHS) is pleased to submit this seventh report to Governor Pritzker and members of the General Assembly. The report focuses on the status of children age three (3) through the age of twenty-one (21) who are currently receiving services in institutional settings funded by the DHS or the Department of Healthcare and Family Services (HFS). It also discusses community-based alternatives to institutional services and efforts by the DHS, Division of Developmental Disabilities (DDD) to ensure children are able to remain in their own homes and communities as much as possible while receiving necessary supports and services to address their developmental disabilities or severe emotional disorders.

Overview

Developmental Disabilities Overview

During FY2019, approximately 1637 children and adolescents age three (3) through the age of 21 with developmental disabilities received services. The majority of these youth (1471 or 90%) were served in their own homes or small group homes in the community through community agencies and funded by DHS/DDD. For FY19, 166 children (10%) received services in large institutional settings. Of the 167 children receiving services in a large institutional setting, 24 were served through DHS/DDD funded settings and 143 were served through HFS funded settings.

There are three types of large licensed residential settings in which children with developmental disabilities may be served if alternative community-based services are unable to meet the child's needs.

- Private Child Care Institutions (CCI), also called Residential Schools, are licensed by the Department of Children and Family Services and funded through DHS/DDD.
- Private Skilled Nursing Facilities for Pediatric (SNF/PEDS) are licensed as Long-Term Care for Under Age 22 Facilities by the Department of Public Health. These facilities are certified for participation in the federal Medical Assistance Program (Medicaid) as

Intermediate Care Facilities for individuals with Developmental Disabilities (ICF/DD) and funded through HFS.

- Public State-Operated Developmental Centers (SODC). These facilities are certified for participation in the federal Medical Assistance Program (Medicaid) as Intermediate Care Facilities for individuals with Developmental Disabilities and funded through DHS/DDD.

Severe Mental Illnesses/Severe Emotional Disturbance (MI/SED) Overview

On September 10, 2015 HB 4096 was signed resulting in Public Act 99-0479. This act transferred the Individual Care Grant Program from the Illinois Department of Human Services, Division of Mental Health to the Illinois Department of Healthcare and Family Services. This included, "All books, records, papers, documents, property (real and personal), contracts, and pending business pertaining to the power, duties, rights and responsibilities related to the functions of the Individual Care Grant program." As a result, the Illinois Department of Human Services, Division of Mental Health does not have any information on children with a diagnosis of a severe mental illness or severe emotional disorders, who are currently being provided services in an institution. This information needs to be provided by the Illinois Department of Healthcare and Family Services.

The Illinois Department of Healthcare and Family Services did not provide DHS with the information for this report.

Current Status of Children in Institutional Settings

Developmental Disabilities - Institutional Settings

The status of children in each of the three types of institutional settings is outlined below.

Services in a Child Care Institution

Some children with developmental disabilities, who are unable to remain in the family home, receive services in private Child Care Institutions. Children receiving services in these residential settings are generally children with significant behavior issues or children who have not been successful with home-based or other community-based supports. They typically receive educational services funded by school districts, habilitation, and needed behavior therapy services on a continual basis.

A total of 24 children with developmental disabilities received CCI services during FY19. The average daily cost was \$314, or an annualized cost per child of \$114,785.

Private Medicaid-Certified Services

Some children with developmental disabilities who need intensive nursing care and are unable to remain in the family home receive services in private Skilled Nursing Facilities for Pediatrics (SNF/PEDS). Children receiving services in SNF/PEDS are generally children with significant medical issues as well as a developmental disability. They typically receive nursing assessment, monitoring, intervention, and supervision of their condition or needs on a 24-hour basis, as well as needed habilitation and therapy services.

A total of 143 children with developmental disabilities received SNF/PED services from one of ten facilities in FY19. The average per diem is \$391 with the average annual cost per resident at \$142,914.

State-Operated Developmental Center (SODC)

No children 17 years of age or younger received services in an SODC during FY19. This is the result of strong and ongoing efforts by the Division to keep children at home, in their own communities, in community-based group homes, or Child Care Institutions.

Severe Mental Illnesses/Severe Emotional Disturbance (MI/SED) - Institutional Settings

On September 10, 2015 HB 4096 was signed resulting in Public Act 99-0479. This act transferred the Individual Care Grant Program from the Illinois Department of Human Services, Division of Mental Health to the Illinois Department of Healthcare and Family Services. This included, "All books, records, papers, documents, property (real and personal), contracts, and pending business pertaining to the power, duties, rights and responsibilities related to the functions of the Individual Care Grant program." As a result, the Illinois Department of Human Services, Division of Mental Health does not have any information on children with a diagnosis of a severe mental illness or severe emotional disorders, who are currently being provided services in an institution. This information needs to be provided by the Illinois Department of Healthcare and Family Services.

The Illinois Department of Healthcare and Family Services did not provide DHS with the information for this report.

Community Alternatives

The Division of Developmental Disabilities is committed to working with individuals with disabilities and their families to develop needed community-based supports to assist the individual to remain at home or in the home community, if possible. This is especially important when the individual is under the age of 18.

The Division has a strong and effective pre-admission screening (PAS) process in place. Through the PAS process, individuals are assessed to determine their service needs and eligibility for

specific programs and offered choices from among the services for which they are eligible. Prior to authorizing institutional services, Division staff review pertinent information on each child's needs, service history, and family status to determine whether or not the child can be served successfully through community-based services. Only when community-based services are unable to support the child successfully are institutional options authorized.

Developmental Disabilities - Community Alternatives

In FY19, the Division of Developmental Disabilities served approximately 1471 children in their own homes or in small group homes through community-based services. Since July 1, 2007, the Division has operated two Medicaid Home and Community-Based Services Waivers for Children and Young Adults with Developmental Disabilities aged three (3) through 21. The Children's Support Waiver provides an array of home-based services. The Children's Residential Waiver provides services in a small Child Group Home. An important feature of these children's waivers is that, while participants must enroll in Medicaid, parent's income is not counted in determining the child's eligibility for Medicaid. The Children's Support Waiver replaces an earlier state-funded program of in-home supports, the Family Assistance and Support Program. In FY19, the Children's Support Waiver was authorized to serve up to 1440 children, adolescents, and young adults. The Division may amend to increase capacity as appropriations allow.

The Children's Support Waiver (CSW) is modeled on the adult Home-Based Support Services (HBS) program and features a significant level of family control over services and service providers. During calendar year 2019, each child was awarded \$1,542 per month, twice the monthly Supplemental Security Income (SSI) amount. The family may choose Self-Direction Assistance (SDA) to assist with determining what services are needed, in addition to those available from the schools, Medicaid State Plan, community resources and natural supports. The family and Independent Service Coordination agency staff design a Personal Plan within the monthly maximum that guides service provision to meet the child's needs. The service plan identifies which covered services within the Children's Support Waiver the family chooses, as well as how much of each service is to be delivered. All services must be specified in the individual service plan.

Covered services in the Children's Support Waiver include Self-Direction Assistance, Personal Support, Behavior Intervention and Training, and Training and Counseling for Unpaid Caregivers. Waiver participants may also obtain needed items to address their disability identified in the individual service plan. These may include Home and Vehicle Accessibility Modifications, Adaptive Equipment and Assistive Technology.

In FY19, the Children's Residential Waiver (CRW) was authorized to serve up to 295 children, adolescents and young adults age three (3) through 21 in small community-based group homes serving ten or fewer children. Child Group Homes are licensed by the Department of Children and Family Services. In addition to residential habilitation, this waiver also provides Behavior

Intervention and Training, Adaptive Equipment and Assistive Technology. All services must be specified in the individual service plan.

The two (2) children's waivers are designed to give eligible children community-based options to prevent or delay out-of-home placement or to provide small community-based services instead of institutional services in a Child Care Institution, SNF/PED, or State-Operated Developmental Center.

Severe Mental Illnesses and Severe Emotional Disturbance (MI/SED) Summary and Comparison of Costs

On September 10, 2015 HB 4096 was signed resulting in Public Act 99-0479. This act transferred the Individual Care Grant Program from the Illinois Department of Human Services, Division of Mental Health to the Illinois Department of Healthcare and Family Services. This included, "All books, records, papers, documents, property (real and personal), contracts, and pending business pertaining to the power, duties, rights and responsibilities related to the functions of the Individual Care Grant program." As a result, the Illinois Department of Human Services, Division of Mental Health does not have any information on children with a diagnosis of a severe mental illness or severe emotional disorders, who are currently being provided services in an institution. This information needs to be provided by the Illinois Department of Healthcare and Family Services.

The Illinois Department of Healthcare and Family Services did not provide DHS with the information for this report.

Individual Care Grant Program (ICG)

On September 10, 2015 HB 4096 was signed resulting in Public Act 99-0479. This act transferred the Individual Care Grant Program from the Illinois Department of Human Services, Division of Mental Health to the Illinois Department of Healthcare and Family Services. This included, "All books, records, papers, documents, property (real and personal), contracts, and pending business pertaining to the power, duties, rights and responsibilities related to the functions of the Individual Care Grant program." As a result, the Illinois Department of Human Services, Division of Mental Health does not have any information on children with a diagnosis of a severe mental illness or severe emotional disorders, who are currently being provided services in an institution. This information needs to be provided by the Illinois Department of Healthcare and Family Services.

The Illinois Department of Healthcare and Family Services did not provide DHS with the information for this report.

Summary and Comparison of Costs

The Division of Developmental Disabilities, costs for institutional services are significantly higher than costs for alternative community services. Information on comparative costs is shown for each setting below.

Developmental Disabilities Summary and Comparison of Costs

The chart below summarizes the number of individuals served and the costs for institutional services to children through the age of twenty-one (21) with developmental disabilities.

Developmental Disabilities Institutional Costs for FY19

Program	# Served	Per Diem	Average Annual Cost
Child Care Inst.	24	\$314	\$114,785
SNF/PED	143	\$391	\$142,914
SODC	0	\$ 0	\$ 0
TOTAL	167	\$380	\$138,872

The chart below summarizes the number of individuals served and the costs for home-based or small group home services to children from age three (3) through the age of 21 with developmental disabilities. These services are used for cost comparison purposes because these are the services that would most likely be needed as an alternative to institutional services.

The Division of Developmental Disabilities currently serves approximately 1471 children from age three (3) through the age of 21 in home or community-based services, compared with 167 in institutional settings.

Developmental Disabilities Community Costs for FY19

Program	Average Annual Cost
Children's Residential Waiver - Child Group Home	\$104,890.59
Children's Support Waiver - In-Home Supports	\$16,138.27

Severe Mental Illnesses and Severe Emotional Disturbance (MI/SED) Summary and Comparison of Costs

On September 10, 2015 HB 4096 was signed resulting in Public Act 99-0479. This act transferred the Individual Care Grant Program from the Illinois Department of Human Services, Division of Mental Health to the Illinois Department of Healthcare and Family Services. This included, "All books, records, papers, documents, property (real and personal), contracts, and pending business pertaining to the power, duties, rights and responsibilities related to the functions of the Individual Care Grant program." As a result, the Illinois Department of Human Services, Division of Mental Health does not have any information on children with a diagnosis of a severe

mental illness or severe emotional disorders, who are currently being provided services in an institution. This information needs to be provided by the Illinois Department of Healthcare and Family Services.

The Illinois Department of Healthcare and Family Services did not provide DHS with the information for this report.

Conclusion

The Division of Developmental Disabilities is committed to the principle that children, including those with developmental disabilities or severe emotional disturbance, should be able to remain in their family homes. Only if it is not possible to meet the child's needs at home do we consider authorizing out-of-home services, particularly services in a large institutional setting. The Division carefully reviews each child who is referred for residential services individually to determine what is in the child's best interest.

The Division of Developmental Disabilities is also committed to enhancing the availability and effectiveness of home and community-based services. We recognize these services are significantly less costly to the state. Whenever it is possible to meet a ~~particular child's~~child's needs in the home or through smaller community settings, community-based services are the first options explored.