

State of Illinois

Department of Human Services

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

Bi-Annual Report

March 2014

As Required by Public Act 095-0622

Introduction

Public Act 095-0622 directs the Illinois Department of Human Services on or before March 1, 2014 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 setting 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 third report to Governor Quinn and members of the General Assembly. The report focuses on the status of children through the age of seventeen who are currently receiving services in institutional settings funded by the DHS Divisions of Developmental Disabilities and Mental Health. It also discusses community-based alternatives to institutional services and efforts by both Divisions to ensure that 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 FY2013, approximately 4,423 children and adolescents through the age of 17 with developmental disabilities received services. The vast majority of these youth (4,146 or 94%) are served in their own homes or small group homes in the community through community agencies. For FY13, 277 children (6%) received services in large institutional 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.

1. Private Child Care Institutions (CCI), also called Residential Schools, are licensed by the Department of Children and Family Services.
2. 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/MR).
3. 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.

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

During FY2013, 151 community mental health agencies consisting of 2,557 clinicians provided community based mental health services for 35,868 children and adolescents. In addition to community based mental health services, The Screening, Assessment and Support Services (SASS) System a collaborative effort between the Illinois Departments of: Children and Family Services (DCFS); Healthcare and Family Services (HFS); and, Human Services, Division of Mental Health (DHS-DMH) provided services to over 23,000 unique youth being enrolledⁱ in the SASS program experiencing more than 26,000 total episodes of crisisⁱⁱ. SASS provides pre-admission psychiatric hospitalization screenings to HFS enrolled, unfunded, and under-funded children and youth who are at risk of inpatient psychiatric hospitalization through immediate crisis intervention and stabilization services, support to children and families when a child is

hospitalized, post-hospitalization continuity of care, home-based family support, case management, and needed psychiatric services.

A percentage of youth served through the community mental health system meet the diagnostic criteria for a serious emotional disturbance (SED). These children and adolescents require an intensive, flexible array of community based services that are individually customized in design to reduce the reliance on out-of-home placement, in order to remain safely at home with their families. This service delivery model also incorporates the cultural, linguistic, trauma-informed, socio-economic, and other needs of youth and families requiring services. For the past two years, DMH in partnership with other child serving systems have been engaged in a comprehensive planning, training, and technical assistance process to develop a cross system infrastructure to ensure a System of Care (SOC) framework is developed to meet the unique needs of these children, adolescents, and their families. The services provided through this interagency system of care will offer sufficient intensity and flexibility to support families in maintaining these children and adolescents at home, forestalling more restrictive and costly residential treatment.

There are a percentage of children and adolescents whose SED diagnosis results in a level of care that exceeds the capacity of the community mental health system and families. For these youth, the Department of Mental Health through the Individual Care Grant (ICG) program provides financial subsidies to parents or guardians of these children, to assist them in obtaining the appropriate level of treatment services (residential or in-home/community).

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.

1. 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 72 children with developmental disabilities received CCI services during FY13. The average daily cost was \$171, or an annualized cost per child of \$62,434.

2. 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 205 children with developmental disabilities received SNF/PED services from one of ten facilities in FY13. The average per diem is \$192 with the average annual cost per resident at \$70,080.

3. State-Operated Developmental Center (SODC)

No children 17 years of age or younger received services in an SODC during FY13. This is the result of strong and ongoing efforts by the Division to keep children at home, in their own communities, or in community-based group homes, or Child Care Institutions.

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

The status of children and adolescents receiving services in a residential setting is outlined below.

Individual Care Grants Program (ICG)

The ICG program serves children and adolescents with severe mental illnesses. Families whose children receive grants may choose to use the grant for intensive community-based services or intensive residential treatment service.

Children receiving ICG services in residential settings represent the most seriously emotionally disturbed youth in the state. They typically receive individual therapy, group therapy, family therapy, crisis intervention, psychiatric consultation, and milieu therapy services.

A total of 284 children and adolescents received residential services through the ICG Program during FY2013. They range in age from 10 to 21. The average annual cost per child is \$51,761.

Although the majority of ICG clients are served in residential facilities, it is important to note that families increasingly desire to keep their children home through the use of intensive community-based ICG services. During FY2013 46% of ICG clients were served in the less restrictive in-home settings, while 54% were served in residential facilities. Additional information on in-home services is contained in the section on community alternatives below.

The Department of Human Services Division of Mental Health (DHS-MH) is committed to administering the ICG program consistent with the System of Care Values and current best practices regarding the treatment of children and adolescents with serious emotional disturbances. This begins with promoting education and awareness among parents, guardians and health providers, focuses on prevention and early intervention, includes an evidenced-based system of assessment that identifies children and adolescents strengths and needs, provides an array of levels of care best suited to meet the individual needs of each child/youth.

Community Alternatives

The Divisions of Developmental Disabilities and Mental Health are 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 that is possible. This is especially important when the individual is under the age of eighteen.

Both Divisions have 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 and 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.

1. Developmental Disabilities - Community Alternatives

In FY13, the Division of Developmental Disabilities served approximately 4,146 children in their own homes or in small group homes through community-based services. Children may receive supports through fee-for-service program, particularly respite, or through programs funded through grants-in-aid. These programs are operated by local community agencies that are responsible for making program decisions about individual eligibility and service needs, following general statewide program guidelines.

As part of its ongoing efforts to enhance community services, effective July 1, 2007, the Division initiated two Medicaid Home and Community-Based Services Waivers for Children and Young Adults with Developmental Disabilities aged 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 new 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 FY13, the Children's Support Waiver was authorized to serve up to 1,400 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 2013, each child was awarded \$1,420 per month, twice the monthly Supplemental Security Income (SSI) amount. The family, working with a local Service Facilitator, determines what services are needed, in addition to those available from the schools, Medicaid State Plan, community resources and natural supports. The family and Service Facilitator design an individual service 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 Service Facilitation, 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 FY13, the Children's Residential Waiver (CRW) is authorized to serve up to 280 children, adolescents and young adults through the age of 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 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.

The federal matching funds garnered by these Medicaid waivers are being used, together with Hospital Tax revenues, to provide additional children with developmental disabilities with the community-based services they want and need so they can remain in their own homes or in the community in the least restrictive, most homelike setting consistent with their needs.

2. Severe Mental Illnesses/Severe Emotional Disturbance (MI/SED) - Community Alternatives

The Division of Mental Health served 132 children and adolescents in their own homes through the Individual Care Grant Program (ICG).

Individual Care Grant Program (ICG)

ICG intensive community-based services are designed to meet the unique needs of these children with a diagnosis of Serious Emotional Disorder and may include one or more of four services. ICG treatment plans may include:

- **Therapeutic Stabilization Services:** This is a time-limited clinical intervention designed to integrate individuals into the community.

- Child Support Services: This involves the purchase of community-based specialized therapeutic recreational activities.
- Behavior Management Intervention Services: This is a time-limited child and family training/therapy intervention focused toward amelioration or management of specific behaviors that jeopardize the child's functioning in the home/family setting. This intervention typically teaches/models techniques and skills that can be used by the parent/guardian and other family members.
- Case Coordination: The role of the case coordinator is to help develop the individual treatment plan, monitor its implementation, and coordinate services by the various service providers.
- Any needed combination of the above ICG services.

132 children received ICG intensive community services during FY2013. The average annual cost for ICG intensive community services is \$5,367 per child.

Summary and Comparison of Costs

For both the Division of Developmental Disabilities and the Division of Mental Health, costs for institutional services are significantly higher than costs for alternative community services. Information on comparative costs is shown for each division 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 17 with developmental disabilities.

Program	# Served	Per Diem	Average Annual Cost
Child Care Inst.	72	\$171	\$62,434
SNF/PED	205	\$192	\$70,080
SODC	0	\$ 0	\$ 0
TOTAL	277	\$187*	\$68,093*

*The total cost data are weighted averages.

The chart below summarizes the number of individuals served and the costs for home-based or small group home services to children through the age of 17 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 4,146 children through the age of seventeen in home or community-based services, compared with 277 in institutional settings.

Developmental Disabilities Community Costs For FY13

Program Projected Average Annual Cost

Program	Projected Average Annual Cost
Children's Residential Waiver - Child Group Home	\$81,997
Children's Support Waiver - In-Home Supports	\$12,312

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

The chart below summarizes the number of individuals served and the costs for, residential services to children and adolescents through the age of 21 with severe mental illnesses or severe emotional disturbance.

Mental Health Residential Costs

Program	# Served	Per Diem	Average Annual Cost/Child
ICG - Residential	152	\$250	\$91,250

The chart below summarizes the number of individuals served and the costs for intensive community-based ICG services to children and adolescents through the age of 21 with severe mental illnesses or severe emotional disturbance. This service is used for cost comparison purposes because these are the services that would most likely be needed as an alternative to institutional services.

Mental Health Community Costs

Program	# Served	Per Diem	Average Annual Cost/Child
ICG - Residential	152	\$250	\$91,250

Program Projected Average Annual Cost/Per Child

ICG - Intensive In-Home Supports \$5,367

Conclusion

Both the Division of Developmental Disabilities and the Division of Mental Health are 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 the two divisions consider authorizing out-of-home services, particularly services in a large institutional setting. The Divisions carefully review each child who is referred for residential services individually to determine what is in that child's best interest.

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

ⁱ Figure captures unique youth enrolling in SASS per fiscal year. Figure does not capture youth carrying over from prior fiscal years or youth with extensions only in the stated fiscal year.

ⁱⁱ Episodes of Crisis represents newly initiated eligibility span. A youth may have multiple SASS eligibility spans in a single fiscal year. This count is not a count of unique people.