

State of Illinois

Department of Human Services

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

Second Bi-Annual Report

March 2010

As Required by Public Act 095-0622

Introduction

Public Act 095-0622 directs the Illinois Department of Human Services on or before March 1, 2010 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 beginning in 2010."

The Department of Human Services (DHS) is pleased to submit this second 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 FY2009, approximately 8,121 children and adolescents through the age of 17 with developmental disabilities received services. The vast majority of these youth (7,621 or 94%) are served in their own homes or small group homes in the community through community agencies. For FY09, 500 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:

- Private Child Care Institutions (CCI), also called Residential Schools, are licensed by the Department of Children and Family Services.
- 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).
- 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 FY2009, 44,959 children and adolescents through the age of 21 with mental illnesses (MI) were served by 151 community mental health agencies. Of these, 18,134 met the criteria for Severe Emotional Disturbance (SED). For the purposes of this report, the terms severe mental illnesses and SED are used interchangeably. This group constitutes one third of all children and adolescents served by DMH. The vast majority of these youth are served in their community through community mental health agencies. Of the youth identified as SED, 2% are receiving residential treatment services. Another 2% are receiving intensive community-based Individual Care Grant services.

The Department of Mental Health (DMH) serves very challenging children - those who are unable to remain at home or be served in a child group home and require long-term residential services in Private Child Care Institutions (CCI), also called Residential Schools. CCI's are licensed by the

Department of Children and Family Services and are funded through the Individual Care Grant (ICG) Program. Youth who are served in these residential facilities typically exhibit high levels of aggression and self-destructive behavior, requiring intensive behavioral intervention in a 24-hour, seven days a week continuum of care.

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 252 children with developmental disabilities received CCI services during FY09. The average daily cost was \$175, or an annualized cost per child of \$63,891.

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 247 children with developmental disabilities received SNF/PED services from one of ten facilities in December 2009. Of those, 143 were under the age of 13 and 104 were between the ages of 13 and 17. In addition, 83 SNF/PED residents qualified for exceptional care rates, which are individualized based on each resident's needs. The weighted average per diem is \$225 including the costs of exceptional care. The base SNF/PED per diem is \$185, with the weighted average annual cost per resident of \$82,125.

State-Operated Developmental Center (SODC)

Only one child, who was 17 years of age or younger, received services in an SODC during FY09. 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. The average daily cost for the child was \$403, or an annualized cost of \$147,095.

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

The status of children receiving services in an institutional 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 275 children received Child Care Institution services through the ICG Program during FY2009. They range in age from 7.3 to 17.9. The average annual cost per child is \$105,938.

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 FY2009, 39% of ICG clients were served in the less restrictive in-home settings, while 61% were served in residential facilities. Additional information on in-home services is contained in the section on community alternatives below.

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.

Developmental Disabilities - Community Alternatives

In FY09, the Division of Developmental Disabilities served approximately 7,621 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 new 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 FY09, the Children's Support Waiver was authorized to serve up to 1,100 children, adolescents and young adults. The Division may amend to increase capacity as appropriations allow.

The new 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. Each child is currently awarded \$1,348, 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 FY09, the Children's Residential Waiver (CRW) is authorized to serve up to 201 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.

Three providers of Child Care Institution services have approached the Division to discuss voluntarily transitioning residents into smaller Child Group Homes funded through the CRW. These discussions are ongoing.

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.

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

The Division of Mental Health served 145 children and adolescents in their own homes through the Individual Care Grant Program (ICG). An additional 75 children and adolescents were served in Child Group Homes.

Individual Care Grant Program (ICG)

ICG intensive community-based services depend on the needs of the child 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.

145 children received ICG intensive community services during FY2009. The average annual cost for ICG intensive community services is \$20,356 per child. 75 children and adolescents were served in community-based Child Group Homes at an estimated annual cost of \$103,295 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, for FY09, the number of individuals served and the costs for institutional services to children through the age of 17 with developmental disabilities.

Developmental Disabilities Institutional Costs

Program	# Served	Per Diem	Average Annual Cost
Child Care Institution	252	\$175	\$63,891
SNF/PED	247	\$225*	\$82,170**
Total	500	\$268	\$82,593

Notes:

- * The SNF/PED cost data are weighted averages that include Exceptional Care at an annualized total cost of \$ 20,283,780. Averaging in the Exceptional Care costs gives a weighted average rate of \$225 and a weighted average annual cost per resident of \$82,170. The base SNF/PED rate is \$185 per day.
- ** 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 7,621 children through the age of seventeen in home or community-based services, compared with only 500 in institutional settings.

Developmental Disabilities Community Costs For FY09

Program	Projected Average Annual Cost
Children's Residential Waiver - Child Group Home	\$80,566
Children's Support Waiver - In-Home Supports	\$11,160

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, institutional services to children through the age of 17 with severe mental illnesses or severe emotional disturbance.

Mental Health Institutional Costs

Program	# Served	Per Diem	Average Annual Cost
ICG - Child Care Inst.	275	\$290	\$105,938
Program	# Served	Per Diem	Average Annual Cost
ICG - Child Care Inst.	275	\$290	\$105,938

The chart below summarizes the number of individuals served and the costs for intensive community-based ICG services to children through the age of 17 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	Projected Average Annual Cost
ICG - Intensive In-Home Supports	\$20,356
ICG - Child Group Home	\$103,295

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.