INDIVIDUAL CARE GRANT BRIEF

HISTORY & OVERVIEW

The Individual Care Grant (ICG) program was established by Public Act 76-1943 in 1969. The Act was established to provide financial subsidies to parents or guardians of children with severe mental illness, to assist them in obtaining the appropriate level of treatment services (residential or in-home/community). The management and oversight of the ICG Program is the responsibility of the Child & Adolescent Services Division of the Department of Human Services' Division of Mental Health (DHS-MH).

The administration and operation of the ICG program is governed by Illinois Administrative Code, Title 59 Part 135, commonly referred to as Rule 135[1]. This rule establishes the statutory guidelines for all aspects of the ICG Program including definitions, the eligibility criteria, the application process and the termination of funding and/or services. In order to receive an ICG, Rule 135 requires that an application packet[2] be completed. Completed applications are reviewed for eligibility based on the criteria established in Rule 135. The eligibility criteria are as follows:

- The parent/guardian must be a resident of the State of Illinois.
- The child must have a severe mental illness[3]. A severe mental illness is defined as a mental or emotional disorder which substantially impairs thought, perception of reality, emotional process, judgment, behavior, or ability to cope with the ordinary demands of several life domains. Symptoms must include severely impaired reality testing and may include hallucinations, delusions, avoidance or withdrawal from human contact, marked affective instability, apathy, bizarre behavior, deficient or unusual forms of communication, agitation and/or danger to self or others. The course of the illness should indicate that the symptoms do not represent an acute episode from which rapid and substantial remission is likely.
- There has been an appropriate trial of inpatient, outpatient and/or community-based treatment efforts, and subsequently residential services are required.

[1] Rule 135 can be found at: http://www.ilga.gov/commission/jcar/admincode/059/05900135sections.html
[2] See Appendix for a list of the complete application requirements.
[3] It should be noted, that under Rule 135, severe behavioral problems (i.e. runaway behavior, physical aggression or self-injurious behaviors), do not qualify as a "severe mental illness" unless they are also accompanied by psychosis. This has been the source of significant criticism, as these behaviors, though often severely disruptive and unmanageable for families, schools and communities do not qualify for an ICG in the absence of co-occurring psychotic symptoms. Developmental Disorders (such as Autistic spectrum disorders) are also excluded under the Rule.

- The child must not be under the guardianship of a State agency, or in the legal custody of a State agency.
- The child must be enrolled in an approved educational program at the elementary/high school level.
- A completed application package in accordance with Section 135.40 of this Part must be submitted before the child attains the age of 17 years and six months.

Youth determined to be eligible for the ICG Program may receive in-home/community-based or residential treatment services. While the youth is in the ICG Program, DHS-MH[4] monitors the care, treatment and progress of the youth and recommends when residential treatment is no longer necessary or transition to in-home/community-based services is appropriate.

CRITICISM OF THE ICG PROGRAM

The ICG Program is intended to be consistent with the Individuals with Disabilities Education Act (IDEA) which requires that children with disabilities have the opportunity to receive a free, mainstream education like other children. The residential component of the ICG Program is intended to provide short-term, residential treatment and stabilization for a given period of time for youth who, despite extensive wraparound services, could not be maintained in their schools and/or homes. In recent years, the ICG Program has come under increasing criticism for a variety of reasons. Families and stakeholders have consistently reported that the application process is too complicated, cumbersome and lengthy. Similarly, families and stakeholders have complained that the eligibility requirements are too narrow and do not adequately provide access to ICG services for all the children and families who need them. Additionally there is widespread misperception across child-serving systems that children must be declared ineligible for the Individual Care Grant before they can access other residential services. Finally, families and stakeholders have complained about the decreasing number of approved ICG applications. Of equal concern is the increasing length of stay for children in residential ICG treatment and delays in transitioning them back to their families and community-based treatment services.

[4] DHS-MH or our designee; The Collaborative for Access & Choice (an Administrative Service Organization).

BEST PRACTICES IN CHILD & ADOLESCENT MENTAL HEALTH

The Department of Human Services' Division of Mental Health (DHS-MH) adheres to the system of care approach to addressing the mental health needs of children and adolescents promulgated by the United States Department of Health & Human Services' Substance Abuse and Mental Health Services Administration (SAMHSA) and The President's New Freedom Commission Report on Mental Health. A system of care is a "spectrum of effective, community-based services and supports for children and youth with, or at risk for, mental health or other challenges and their families, that is organized into a coordinated network, builds meaningful partnerships with families and youth, and addresses their cultural and linguistic needs, in order to help them to function better at home, in school, in the community and throughout life"[5]. In partnership with other child-serving agencies[6], providers, consumers and their families, DHS-MH works to establish a statewide, system of care that provides a continuum of approaches to the treatment of children and adolescents with serious emotional disturbance. This continuum begins with education and public awareness, emphasizes prevention and early intervention and extends to crisis stabilization, respite care, inpatient or residential treatment.

ALIGNING THE ICG PROGRAM WITH BEST PRACTICES

DHS-MH is committed to administering the ICG program consistent with these 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 evidence-based system of assessment that identifies youth's strengths and needs, provides an array of levels of care best suited to meet the individual needs of each youth and aggregates and analyzes data on outcomes in order to strengthen and expand those treatment services that are most effective.

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[5] Wotring, J., & Stroul, B. (2011). Issue Brief: The Intersect of Health Reform and Systems of Care for Children's Behavioral Health Care for Children and Youth with Mental Health and Substance Use Disorders and their Families. Washington, DC: Georgetown University Center for child and Human Development, National Technical Center for Children's Mental Health. Website: http://gucchd.georgetown.edu.

[6] DHS-MH C&A Services Division collaborates with the Department of Children & Family Services, the Illinois Children's Mental Health Partnership, the Department of Juvenile Justice, the Illinois State Board of Education and the Department of Healthcare & Family Services.

After listening to input from family members and other key stakeholders and conducting our own internal review, DHS-MH believes that the ICG Program should be restructured and Rule 135 revised[7] to be more consistent with current best practices and better meet the needs of families with children with a diagnosis of serious emotional disturbance. This revision should include a thorough examination of the application process, eligibility criteria, monitoring and utilization review and return to in-home/community-based living. In revising the ICG Program, one goal is to provide shorter periods of residential stay and mainstream children with disabilities back into the community with appropriate and necessary wraparound community services. Concomitant with the revision of Rule 135, DHS-MH is committed to pursuing the annual reinvestment of lapsed ICG funding into strengthening the infrastructure of community-based, mental health services for children & adolescents. Reinvesting lapsed ICG funding, will enable DHS-MH to partner with community agencies to offer a broader array of treatment services, supports and alternatives than offered currently under the ICG Program or in the current taxonomy of Rule 132[8] services. However, this will require legislative action on the part of the General Assembly to enact the requisite legislative changes. In addition, DHS-MH is collaborating with key stakeholders to conduct a retrospective, multi-year, clinical review of approved and denied ICG applications. The goal is to clinically differentiate these two populations, in terms of both strengths and needs, in order to begin developing additional levels of care within the ICG program to better serve children with a diagnosis of serious emotional disturbance and their families.

NEXT STEPS

DHS-MH has retained the services of Dr. John S. Lyons[9] to provide expert consultation on restructuring and improving the ICG Program. Dr. Lyons will join DHS-MH at the October 18, 2013 Illinois Mental Health Planning and Advisory Council C&A Subcommittee meeting devoted to the topic of the ICG Program and will facilitate a discussion of developing a shared vision for services to children and adolescents with

[7] Rule 135 was last revised in 1999.
[8] Rule 132 refers to Illinois Administrative Code Title 59, Part 132 Medicaid Community Mental Health Services Program.
[9] Dr. Lyons is the Endowed Chair of Child & Youth Mental Health at the University of Ottawa, School of Psychology. He is the Editor of the Journal of Residential Treatment for Children & Youth and an internationally renowned expert in the area of mental health needs of children and adolescents. Dr. Lyons previously reviewed the ICG Program in 1990.

serious emotional disturbances and their families. At this meeting, DHS-MH will announce our intention to revise Rule 135 and restructure the ICG Program and will solicit the participation of key stakeholders, expert clinicians and family members to help guide and inform the process. DHS-MH will organize and convene five workgroups, co-chaired by key stakeholders, to work on various aspects of the ICG Program restructuring and Rule 135 Revision. The five workgroups will be:

- Rule Revision: Application[10], Eligibility & Appeals
- ICG Levels of Care & Community Infrastructure
- Outreach & Training
- Data Analysis & Outcome Measurement
- Financing and Legislation

Our goal is to have a draft revision of Rule 135 completed by January 15, 2014 and to have the other subgroups complete their work by February 28, 2014.

DHS-MH is committed to collaborating with state leaders, consumers, providers, provider organizations and interagency partners in order to restructure and strengthen the ICG Program into one that is better aligned with best practices, embraces system of care values, provides an array of levels of care to best meet individual treatment and provides meaningful and effective strategies to meet the mental, emotional, social and behavioral health of each child and his/her family. DHS-MH believes that by restructuring the ICG program to be better aligned with system of care values and best practices, we can improve the quality of mental health services provided and better serve the children and families of the State of Illinois.

[10] DHS-MH is committed to improving parental access to technical assistance support for completing ICG applications.

APPENDIX

ICG APPLICATION REQUIREMENTS

An ICG/MI application is complete and ready for eligibility determination review when it contains the following required documents:

1. Completed application package checklist (DMHDD-230);
2. Completed application form (DMHDD-231);
3. Completed DMHDD-403c, Financial Questionnaire;
4. Copy of the child's birth certificate;
5. Copy of the child's Social Security card;
6. Copy of the court order defining custody or non-parental guardianship, if appropriate;
7. Psychiatric evaluation dated within 90 days before the current application submission including mental status examination, a specific principal diagnosis and all other diagnoses, medications, treatment summary and recommendations;
8. A written summary of all trials of less restrictive treatment within the past 12 months;
9. Psychological evaluation dated within the past one and one-half years, describing both intellectual and personality functioning;
10. Social and developmental history from early childhood to present;
11. Proof that a child is enrolled in an approved educational program at the elementary/high school level; and
12. Parent/guardian request for eligibility determination and verification of review by parent/guardian of the clinical information submitted (DMHDD-232).