Individual Care Grant Parent Handbook

This handbook is not an official publication of the Department of Human Services, the Division of Mental Health, the Illinois Mental Health Collaborative, or the Individual Care Grant Program. It is the product of research and experience by ICG Parents. This handbook is to be used only as a guide – and is not the final say about what is best for your child. You are.

June 2010

Dedication

This Handbook is dedicated to all the ICG children, adolescents and young adults who know firsthand the struggles of severe mental illness as well as to their parents/guardians and siblings who continue to walk with them on this journey. You are the heroes.

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Overview

Introduction

The Individual Care Grant is a financial supplementation provided by the State of Illinois to assist parents or private guardians in paying the costs of community-based or residential care for children with mental illness under the age of 21 who have not graduated from high school.

Effective treatment of children and adolescents with mental illness requires a partnership between the families of these children, various service providers and agencies. These include, but are not limited to, the Division of Mental Health, the Illinois Mental Health Collaborative, community mental health agencies, residential treatment facilities, school districts, park districts, professionals and other private providers. This partnership is based in a value of collaboration and cooperation between all those concerned with the welfare of our children and who provide for them in one or more areas of their life. The information contained in this Handbook, and the assistance we hope it provides parents/guardians, stems from this value.

Values and Principles for the System of Care

Children's mental health service delivery has undergone a major change during the past fifteen years. The introduction and implementation of the Child and Adolescent Service System (CASSP[1]) has required a thorough reform of how children's mental health services are conceptualized and delivered. The State of Illinois and the Individual Care Grant Program support the core values and guiding principles of the CASSP model:

Core Values

1) The System of Care should be child centered and family focused, with the needs of the child and family dictating the types and mix of services provided.
2) The system of care should be community based, with the locus of services as well as management and decision-making responsibilities resting at the community level.
3) The system of care should be culturally competent, with agencies, programs, and services that are responsive to the cultural, racial, and ethnic differences of the population they serve.

Guiding Principles

1) Children with emotional disturbances should have access to a comprehensive array of services that address the child's physical, emotional, social, and educational needs.
2) Children with emotional disturbances should receive individualized services in accordance with the unique needs and potentials of each child and guided by an individualized service plan.
3) Children with emotional disturbances should receive services within the least restrictive, most normative environment that is clinically appropriate.
4) The families and surrogate families of children with emotional disturbances should be full participants in all aspects of the planning and delivery of services.
5) Children with emotional disturbances should receive services that are integrated, with linkages between child-serving agencies and programs and mechanisms for planning, developing, and coordinating service.
6) Children with emotional disturbances should be provided with case management or similar mechanisms to ensure that multiple services are delivered in a coordinated and therapeutic manner and that they can move through the system of services in accordance with their changing needs.
7) Early identification and intervention for children with emotional disturbances should be promoted by the system of care in order to enhance the likelihood of positive outcomes.
8) Children with emotional disturbances should be ensured smooth transitions to the adult service system as they reach maturity.
9) The rights of children with emotional disturbances should be protected and effective advocacy efforts for children and youth with emotional disturbances should be promoted.
10) Children with emotional disturbances should receive services without regard to race, religion, national origin, sex, physical disability, or other characteristics, and services should be sensitive and responsive to cultural differences and special needs.

[1] CASSP Technical Assistance Center, Center for Child Health & Mental Health Policy, Georgetown University Child Development Center

Family Driven Care[2]

The Individual Care Grant Program also incorporates the principles of family driven care. Family-driven means families have a primary decision making role in the care of their own children. The grant may be utilized to provide in-home community-based services so that the child can remain in his/her home, school, and community. The grant may also be utilized for residential placement in an ICG approved facility. The following are the guiding principles of family-driven care:

Guiding Principles

1) Families and youth, providers and administrators embrace the concept of sharing decision-making and responsibility for outcomes.
2) Families and youth are given accurate, understandable, and complete information necessary to set goals and to make informed decisions and choices about the right services and supports for individual children and families.
3) All children, youth, and families have biological, adoptive, foster, or surrogate family voice advocating on their behalf and may appoint them as substitute decision makers at any time.
4) Families and family-run organizations engage in peer support activities to reduce isolation, gather and disseminate accurate information, and strengthen the family voice.
5) Families and family-run organizations provide direction for decisions that impact funding for services, treatments, and supports and advocate for families and youth to have choices.
6) Providers take the initiative to change policy and practice from provider-driven to family-driven.
7) Administrators allocate staff, training, support and resources to make family-driven practice work at the point where services and supports are delivered to children, youth, and families and where family and youth run organizations are funded and sustained.
8) Community attitude change efforts focus on removing barriers and discrimination created by stigma.
9) Communities and private agencies embrace, value, and celebrate the diverse cultures of their children, youth, and families and work to eliminate mental health disparities.
10) Everyone who connects with children, youth, and families continually advances their own cultural and linguistic responsiveness as the population served changes so that the needs of the diverse populations are appropriately addressed.

[2] Federation of Families for Children's Mental Health, 2008.

Recovery and Resilience[3]

Recovery and resilience are two of the desired outcomes of the services provided by the Individual Care Grant Program.

Recovery is the process in which people are able to live, work, learn, and participate fully in their communities. Recovery is the ability to live a fulfilling and productive life despite a disability. For some, recovery implies the reduction or complete remission of symptoms. Hope plays an integral role in an individual's recovery.

Resilience is the personal qualities to enable an individual to rebound from adversity, trauma, tragedy, threats, or other stresses and to go on with life with of sense of hope and competence. Resilience is cultivated by the infusion of positive childhood experiences and the support of family members and the communities.

[3] The Mental Health Commission Final Report, 2003. http://www.mentalhealthcommission.gov/reports/FinalReport /FullReport.htm.

Program Overview

The complete ICG Rule can be found in the Illinois Administrative Code 59: Mental Health, CH. I Part 135 amended at 23 Ill. Reg 1628, effective January 25, 1999.

Eligibility criteria

Section 135. 30 of the Illinois Administrative Code states that once the ICG is awarded, the parent/guardian has the following responsibilities:

a) The parent/guardian must participate in the child's care, treatment and discharge to family and community.

In February of 2000, the ICG Annual Review process was initiated. A determination of continued eligibility is made for each ICG recipient on the anniversary of the initial determination of eligibility. Continuing eligibility is based on parent participation in treatment, clinical information supporting the current level of care received from the provider and medical necessity. Parents find it helpful to keep a log with dates of all family therapy sessions; contacts with your child; and other important events. This makes it easier to document their involvement at the time of each annual review to re-determine eligibility.

b) All public sources of financial support available to or for the child, including but not limited to Social Security benefits (SSA) and supplemental security income (SSI) must be applied to the costs of residential care, to the extent provided by law. *(Please refer to Financial issues in Overview for more information)*

c) If the child is not already receiving SSI benefits, the parent/guardian must initiate an application for SSI immediately after placement.(*Please refer to Financial issues in Overview for more information)*

d) The parent/guardian must notify the Collaborative of any changes in the level of financial support from public sources. Declaration of ineligibility, reduction of benefits or loss of benefits through the actions of another governmental agency will not affect continued funding, *unless* these actions are the consequences of the parent/guardian's failure to pursue benefits or comply with the ICG Rule.

e) All financial assets of the child exceeding an exempt amount established by the Department must be applied to the costs of residential care. The determination whether certain assets may be exempt is subject to the Department's review and approval.

Currently the exempt amount is $2,500. The Department will subsidize residential and community based expenses when assets are below $2,500.00.

f) The parent/guardian must notify the Collaborative of any changes of address for the parent/guardian.

It is important to remember that if the parent/guardian moves out of the State of Illinois, the child is no longer eligible for the ICG. It is also very

important that the ICG program always have your most recent address and a way to contact you during the day if needed. You must mail or fax written notification of your new address and phone number to the Collaborative. Their information is located on page 57 of this handbook.

g) The parent guardian must notify the Collaborative of any changes of guardianship/custody.

Remember that in order to continue to meet eligibility for the ICG, the child must not be under the guardianship of a State agency, or in the legal custody of a State agency.

Individual Services Plan Development

Section 135.81 outlines steps to follow now that your child has been found eligible to use the grant.

a) When the individual has been determined eligible, the Collaborative will refer the parents/guardian to the appropriate SASS agency for the purpose of developing an individual service plan.

b) At the individual services planning meeting the parent/guardian will consider available residential options and may consider alternative in-home/community service options, in lieu of residential placement, if the alternative services meet the needs of the individual and are recommended by the SASS program supervisor.

Currently, at the services planning meeting, the parent/guardian, the Collaborative, and the ICG/SASS worker will have a conference to determine how the grant will be utilized.

c) The development and/or implementation of an individual services plan may be deferred for one or more of the following conditions:
1) Continuing hospitalization is required;
2) Extended absence from the family due to runaway or a court ordered transfer of custody or guardianship to a governmental agency; or
3) The parent/guardian does not wish to initiate any services with ICG/MI funding or fails to participate in the individual services planning.

d) If the individual service plan is not developed and/or implemented within one year after the date of approval for eligibility, *the parent/guardian must reapply to obtain ICG/MI funding. (*Italics added for emphases.)

It is important to remember that YOU CAN NEVER LOSE the Individual Care Grant because you register complaints or express differences of opinion with or about a provider of community-based services, residential placement services, the Collaborative, or the ICG program.

You Choose How to Use the ICG

Now that your child has the Individual Care Grant, it's time to decide how to use it. The Individual Care Grant can be used in one of two ways: for community-based services while the child lives at home or residential treatment out of the child's home. You will probably hear many different opinions about what "is best" for your child. You may feel criticized if you don't do it "their way". Chances are also good that you are feeling exhausted and worried, having tried a variety of services, treatment, medication(s) and parenting techniques with little success. You doubt your ability to "do anything right" let alone get more services for your child with a mental illness. Where do you begin??

First of all-take a deep breath and relax. You need to get focused on what you **have** accomplished. First and foremost remind yourself that you have stuck by your child through times that most people can't even begin to imagine. Secondly, you continued to believe in, love and advocate for your child despite their mental illness.... despite those remarks/looks from people who truly have no idea of you and your child's levels of pain. How could they possibly know if they have never gone through it themselves?

Before making your decision, talk with people whose opinion you respect, especially other parents of children with mental illnesses. Learn more about these new options. This is a good time to consider joining the ICG Parent Yahoo Message Group where you will receive invaluable support and information. See the ICG Parents Group section of this Handbook for additional information and directions for joining. Listen to your gut feelings. Meditate or pray. Then make your decision. If necessary, your decision can always be revised. Remember the ICG grant is family driven. There is no "one right way" to treat all children with a mental illness. However, common sense and research both suggest that the most effective treatments include supporting, enhancing and maintaining family relationships and keeping the child with a mental illness connected to caring people. Other sections of this manual will outline how to choose and implement a community-based or residential treatment program. The final choice is yours.

The ICG and Education Law

The ICG Rule requires that your child be enrolled in a recognized public school or an approved nonpublic special education facility (ICG Section 135.20). The Collaborative will request that you apply to the local school district for the tuition costs associated with placement (ICG Section 135.90). If an ICG is awarded, the Illinois School Code requires that a school district be responsible for the cost of any in-state educational program regardless of where the child resides in care. The School Code also requires that the responsible school district be notified by the parent or guardian prior to placement. It is recommended that this notification be done in writing to avoid any confusion.

In order for your child to participate in an educational program it must be approved by the Illinois State Board of Education (ISBE). While ISBE has approved many educational programs associated with out-of-state residential facilities, you should verify the program's status before considering placement. A new program may be approved but it is a time-consuming process

which will delay your child's placement.

Individualized Education Program (IEP

The IEP is a written plan describing the needs of your child and what you and the school will do to give your child the extra help and attention needed. Your school district must have an IEP for each eligible child. It is important that you know and understand what goes into an IEP since parents help in developing this plan for their child. You should also understand what happens at IEP meetings and what will happen after the IEP is written.

If you want to increase your understanding of this process you can access the **Educational Rights and Responsibilities: Understanding Special Education in Illinois publication at http://isbe.net/spec-ed/html/parent_rights.htm**

High School Graduation Impact on ICG

The reasons for termination of an ICG are discussed elsewhere in this Handbook. One of those is graduation from high school. The ICG Rule also requires that termination of funding will occur when a child is no longer enrolled in an approved educational program or has turned 21 years of age. To maximize benefits from the Individual Care Grant, it is recommended that you *carefully* coordinate the timing of the transition services and graduation obtained through the educational IEP.

There is confusion around the age issue as the Individual with Disabilities and Education Act (IDEA) requires that students with IEPs can continue in an educational program through age 21 (1 day before age 22). Again, ICG eligibility ends when the student accepts the diploma or becomes 21.

Over the years, an evolving body of case law has supported using the IEP as the standard for graduation instead of using traditional academic credits. This means that meeting the goals and objectives is more important than obtaining credits. Parents/guardians should explore with their local school district the use of the IEP as the standard for graduation. This is an IEP team decision and the parent or youth (when over 18) are full members of this team.

Lack of resources in various communities is another area of concern of ICG parents/guardians. A youth with an IEP cannot be denied services because a school district lacks a particular program or resources. If appropriate resources do not exist within a local district, it is the district's obligation to locate and provide those resources regardless of cost. IDEA is a mandate, therefore, when a youth is identified with an IEP, the youth must be served. The failure to serve is a denial of a free appropriate public education under IDEA.

Transition Services

The ICG and Transition Services

The word 'Transition' is defined by Webster's dictionary as "a passage from one place to another". Children with a mental illness and their families have, and will continue to experience, transitions in a variety of ways. Children becoming teenagers, becoming young adults, getting jobs, going to college/vocational school, desiring healthy age appropriate independence. These transitions can be challenging times for any family. Add "severe mental illness" to that challenge and, if not planned for appropriately, can become genuine clinical setbacks. As a result, there are federal educational laws and state funded (Division of Mental Health and Division of Rehabilitation Services) transition programs that are intended to address/prevent these setbacks.

What is important is that you remember to ALWAYS include transition services in treatment and educational plans at the appropriate times. If thoughtfully planned for, "the transitions of life difficulties" can be made less bumpy for your child, while maximizing the benefits from the above programs.

Transitional planning through Education

Schools are required to provide individualized transition planning for all students who will reach the age of 14 during the school year and for younger students as appropriate. Transition planning is a process that must consider the post-school goals of youth with disabilities in the areas of employment, post secondary education and community living alternatives. The school must invite other non-education service provider agencies that can or are currently providing the services that will assist the student in attaining his or her post-school goals in the above areas. Parents/guardians may provide the school with a list of these agencies and request that they be invited.

There are specific transition documentation requirements for schools that can be found in **Educational Rights and Responsibilities: Understanding Special Education in Illinois publication at http://isbe.net/spec-ed/html/parent_rights.htm**

ICG Adult Transition Services

When a child reaches the age of 17 they enter a period of formal "transition" to adult mental health services. Though children will remain eligible for the Individual Care Grant (assuming the grant is renewed in the annual review process) until high school graduation or the age of 21, whichever comes first, planning for adult services often takes over one year to achieve and must be planned well in advance. Upon reaching age 17, the child's ICG information is referred to the ICG Transition Manager, who will review the status of the child's placement and facilitate the transition. The Transition Manager will send clinical information on the child to the appropriate adult mental health network. The adult network is selected based on the geographical location of the parent/guardian's residence. The adult network, in collaboration with the residential treatment program and/or the ICG/SASS worker will maintain responsibility for assisting the family in developing a plan to transition the child to adult services. The adult services may

include mental health, vocational and living arrangements. The ICG Program has a limited amount of “Transitional Funding” that maybe available to assist the former ICG recipient in developing community based adult services for up to one year following their discharge from the ICG program.

Plans for the child’s transition should be completed and in place at the time they graduate from high school or turn age 21, whichever comes first. If your child is in need of independent living services it is especially important that this process begins early because these services require extensive planning. Parents, youth and the adult network are involved in this process.

The transition service process is essentially the same for children receiving either community or residentially based ICG services. If your child is in residential treatment, you as parent/guardian should expect more involvement from the residential provider and the ICG/SASS worker. If your child is using ICG services in the community, your ICG/SASS worker should also be more involved.

The following is an example of the transition to adulthood process:

Time Frame	Activity	Responsible Party	Final Result
Child reaches age 14	IEP includes transition to adult services in goals, begins to plan for needed resources	Education system in either community or RTC. Parent may need to remind education to address.	Accurate assessment and plan for adult education/ vocational needs, updated at each IEP meeting.
Child reaches age 16	Child, Family & community providers have more focused discussions on adult needs	Family, mental health providers, recreation providers, other community supports	Ongoing dialog bringing all parties together to develop plan.
Child reaches age 17	ICG information sent to adult mental health network	ICG program	Adult mental health network is aware of child's status and pending transition to adult services
Child reaches age 17	Ongoing planning involving young adult, family, education, mental health providers (SASS or RTC),	Family to insure that appropriate systems are engaged. Should expect significant assistance from RTC, SASS, adult network and Education systems.	Needed resources are identified and acquired.
Child reaches age 18	Young Adult is eligible for adult mental health services.	Mental Health providers and family	Young adult is engaged in mental health care that will follow them into adulthood
Child graduates from high school or reaches age 21, whichever occurs first	ICG funding terminates. Child remains eligible for 1 year of limited "transition" funding to be used for community based support	ICG program, adult network, family.	Young adult has adequate supports to engage in adult education/vocation, recreation, mental health and independent living systems as needed.

For more detailed information refer to the ICG Parent's Transition Handbook in the Files section of the ICG Parent Yahoo Group. The group is located at this web address, http://health.groups.yahoo.com/group/IllinoisICGParents/. You must be a member of the group to access the handbook.

Additional education requirement: Age 17 – the IEP must reflect that the student and parent/guardian have been notified that the education rights under IDEA transfer to the student at age 18 unless the parent/guardian take steps to retain guardianship or obtain educational power of attorney. The school district, day school, or residential school is responsible for informing both the student and the parent/guardian, and for documenting this action in the IEP.

Using the ICG for Community Services

Community Based Options

This option allows your child to remain at home or serves as a factor in determining discharge (which may be a shorter stay) in a residential facility. A treatment plan for community-based services should be developed including you and the ICG/SASS worker to reflect all services to be rendered. Note that these services can be changed at any time given the level of functioning of your child.

The Collaborative does not need to approve/disapprove these plans. The Annual Review will include all services rendered to your child including clinical services. The quarterly report will include information that should indicate how your child is functioning with the level of care. This information provided by the ICG/SASS worker will be helpful at the Annual Review.

ICG Child Support Services

The ICG may be used to purchase community activities for your child that the parent/guardian may not otherwise be able to pay for. These activities should help the child improve social skills and peer relationships in the community and should assist in treating the child's mental health problems.

Examples of services covered by this category include:

- Recreation activities through YMCA, Park District or health club membership
- Special recreation programs

Your ICG/SASS Worker will be able to offer a more comprehensive list of examples.

If the cost for the activities exceed $1,570 per fiscal year, a cost request has to be submitted (by the ICG/SASS worker) to the Collaborative for continued approval.

Transition to Adult Services

The grant may be used to purchase transitional services for young adults who are age 18-21 and has graduated from high school. These services are designed to help the youth gain essential skills towards independence. For example, a youth who wishes to live independently will need skills regarding cooking and money management. A class at a local community college may be purchased with ICG funds to assist in learning adult living skills.

Therapeutic Stabilization

This service may be purchased to help improve certain behaviors related to a mental

illness or to learn new skills. An adult who has been trained to provide this service (different from a therapist or counselor) would be assigned to work with the child on a one-to-one basis. Sometimes this service is provided within the home setting, but more often it is provided out of the home to help the child learn to interact appropriately with other people. For example, the worker may go with the child to a recreation program and support the child's efforts to participate in the activities. The worker may help a child or adolescent rebuild social skills or learn how to use public transportation. The parents, the child and the worker should agree on specific activities. Sometimes you will hear this service called respite or mentoring.

ICG Behavior Management Intervention

The ICG may be used to purchase special expertise to teach the family and child how to manage the child's problems at home. These services are only available on a short-term basis and must be beyond what the community mental health agency can provide. Examples of services included in this category are:

- Dietician or fitness consulting to help a child who has gained weight as a side effect of psychiatric medications.
- Behavior specialist who develops a plan for managing certain behaviors.

If the cost per fiscal year exceeds $3,000, a cost request has to be submitted to the Collaborative (by the ICG/SASS worker) for continued approval.

Financial Issues

When your child is living at home you are responsible for most of their financial needs (beyond what is covered by the ICG) arising out of their illness. However, there are some circumstances where assistance may be available.

Social Security

Children and youth with a mental illness living at home may be eligible for SSI benefits. However, if the child is under 18 the family income will be considered in determining whether or not the child is eligible. You should check with the Social Security Administration to determine what income will be considered.

Private Insurance

Your child should be covered under your family health insurance policy. If so, the insurer will be billed for medical and dental services in the usual way. Additionally, all medications, psychiatric monitoring and medication administration may be billed. You are ***strongly*** encouraged to check with your insurance company to determine what services are covered by your policy.

Adoption Subsidy

If your child with a mental illness was adopted through the Illinois Department of Children and Family Services (DCFS), you may be eligible for a subsidy and/or Medicaid. You should contact DCFS to determine what assistance may be available.

Medicaid

Parents may apply for Medicaid health care assistance through your local public aid office. If your child has qualified for SSI, approval will be automatic. As with Social Security, family income will be considered for a youth under 18 years of age.

If your child receives Medicaid and you also have private insurance, you should inform service providers of **both** policies. Providers generally know how to handle this situation. The basic rule is: Medicaid is always secondary, therefore, private insurance will be billed first.

Community-Based ICG Planning

Parental Involvement/Partnering with a mental health agency

The services for Community Based ICG must be managed through the ICG/SASS Worker in your local SASS. The SASS agency will handle the billing and payment for the services in the plan.

The Collaborative will notify you of your SASS agency in your ICG approval letter. Should you move to another community or need additional clarification, you can contact the Collaborative for assistance at 773 794-4884

Treatment Plan Development

The treatment plan should outline what services will be provided for your child in the community. Your child's needs and issues should be discussed in order that the ICG/SASS worker can offer suggestions regarding appropriate services. You should also feel free to make suggestions during this discussion. If at all possible, your child should be present and encouraged to participate in the discussion regarding his/her needs. The treatment plan, when completed, should describe:

- The needs and/or issues the plan is to address
- The goals for each need/issue
- Each service that will be provided
- How often the service is to be provided
- Timelines for services

The treatment plan is required for billing and is maintained at the ICG/SASS agency. It is included in the quarterly review that is submitted to the Collaborative. You, the

parent/guardian, should approve and retain a copy of the final plan.

Case Management

Case management is an essential service that helps tie the treatment plan together and plays a critical role in the system of care for your child. It involves:

- Brokering service for individual children
- Advocating on children's behalf
- Ensuring that an adequate treatment plan is developed and implemented
- Reviewing progress
- Coordinating services
- Aggressive outreach to the child and family
- Working to assure that all needed services and supports are in place

While you, as the parent, are always the overall "case manager" for your child, a skilled and knowledgeable case manager can be an invaluable resource in locating and arranging services. In the ICG Program the case manager is the ICG/SASS worker.

Many different areas may need to be navigated depending on the needs of your child. For example, the worker may need to contact recreation, education and employment agencies. Thus, the need for an invested case manager is vital. The case manager should make sure that everyone is working together in the best interest of your child.

Quarterly and Annual Reviews

Quarterly and Annual Reviews are required under Rule 135. The award dates determine when the Reviews are due. Parental community quarterly reports are important but are not considered as part of the review process. This information assists the Collaborative Clinical Care Managers with their perception of the functioning level of your child. The quarterly report includes questions regarding level of functioning, compliance with rules and medications, school attendance, response to ICG services, clinical intervention, family involvement and crisis intervention.

Parental participation in the Annual Review is critical. It is important that this report be submitted in the allotted timeframe to avoid disruption of care to children in the program. Parents/guardians who are delinquent will receive a second notice to submit review materials. If the second notice is not complied with, your child's funding is in jeopardy.

The Rule specifies that parents/guardians should be notified six weeks prior to the grant anniversary date to determine continuing eligibility for ICG funding. In order to make sure that the notices are giving parents/guardians and providers enough time to respond, the Collaborative will send them sixteen weeks prior to the grant anniversary date. Annual Review material should be submitted to the Collaborative by the thirteenth week prior to the grant anniversary date.

Annual Reports will include: diagnoses, medication and symptoms targeted, therapeutic services, treatment plans and other information as appropriate.

Clinical Appeals

As a result of the Annual Review, a child may have his/her level of care changed (step-up or step-down). If the parent/guardian disagrees with the change in level of care, the parent/guardian may initiate a Secretary's Level of Appeal by writing: M. Kamran, M.D. c/o Illinois Mental Health Collaborative for Access and Choice, POB 06559, Chicago, IL 60606.

Residential Treatment Options

Choosing a placement

1) **SASS Involvement.** Your ICG/SASS is available to help you locate a residential facility. They are available to help with: selecting facilities to call; calling facilities and sending information packets about your child to facilities that meet your criteria for placement. Let your ICG/SASS worker know how you would like assistance.
2) **Facilities List.** DMH contracts with various Illinois and out-of-state residential facilities. A list of these facilities was sent to you with your child's ICG application. You may obtain the latest revision from your ICG/SASS worker. While there are both in-state and out-of-state placements listed, it is important to know that prior to considering an out-of-state placement, it is required that families seek admission to and be denied in writing by three in-state placements in order for an out-of-state placement to be approved. So at first, it will be important to consider the in-state options listed.

Questions to Ask. The following are suggested questions for a residential facility you are evaluating. The ICG Advisory Council prepared this list.

Before the initial visit:

1) Ask for the following in writing prior to your visit: program description, policies and procedures regarding home visits, phone calls (receiving and initiating), behavior management, crisis intervention, physical restraint, safety issues, participation in religious services and activities, meals, activities available after school/evenings/weekends, medical and therapeutic services, transition procedures to home/community, etc. Also, review the placement’s website for this information or request it from your ICG/SASS worker.
2) Read all the above and observe during the visit that the information you were provided matches what you are seeing and hearing.
3) Ask to visit the specific building or unit where your child will most likely be residing.
4) Is the residential facility accredited? By whom? Ask what the requirements are for their particular accreditation and a copy of the last review of their facility completed by the accrediting agency.

During the initial visit:

1) If you did not receive copies of the facility's policies and procedures prior to the visit ask again. Don't leave without them.
2) Try to visit during a time that the residents are at the home and engaged in their typical daily routines. Make a point to observe interactions by the staff with the residents while on your tour. Please know that you may have to sign an acknowledgement regarding maintaining the confidentiality of any residents you see while visiting and/or that your access to see residents might be limited due to privacy issues.

3) Ask to see sample schedules of activities for after school, evenings and weekends. Take copies home with you if possible.
4) What are the job duties of the person showing you around? You'll want to talk to, and ask questions of, one of the staff who are actually working in that residence on a consistent basis, not an intake worker or someone who just stops in once a week to conduct a group therapy session.
5) What is the staffing pattern at the residence? Are people assigned to work the same shift several days in a row or is a different person working every afternoon, evening? What is the turnover rate for residential workers and therapists?
6) What accommodations are made for residents who have allergies to foods, laundry detergents, soap, mold, etc?
7) Ask if your child will have to give up his/her medical doctor, psychiatrist, and therapist and refer only to the facility's personnel? Is the facility willing to work with doctors and therapists you and your child already have a relationship with? Will your child's medication be changed by the medical staff of the facility immediately upon moving in? Who will monitor your child's medication?
8) Ask about the staff's training, e.g. behavior management, crisis intervention, for medical emergencies, etc.
9) Does the staff stay in touch with school personnel? How? How often? Will you have to request their input and/or presence at every IEP meeting?
10) Is the facility clean? Paint peeling? Furniture and carpeting in good repair? Are you comfortable with your child actually living in this environment? Remember that this is not a short vacation.
11) When deciding what to tell the potential placement about your child, you will best be served if you are open and honest about what your child's particular challenges are. You want to know if, and how, the program will typically respond to your child's needs; in particular, you want to know how they will handle any extreme or extraordinary needs your child might have. Describe for them some specific examples of difficult times at home and ask them to provide you with specific information on how they would handle those types of situations. Later compare what they said with their policies and procedures; you want to make sure they are consistent. Are you comfortable with the response? Does the response seem to match with the overall philosophy of the treatment program?
12) Ask about any concerns that are specific to you and your child.
13) Ask how does the facility staff define success for their residents? What is their success rate? Where do the residents go when the placement ends: back to parents home, independent living, college, another residential facility? Does the agency operating the residential facility have adult services/programs that your child could transition into if necessary?
14) Is it possible for you to talk to former residents or parents of former residents?
15) Each program should have a Behavior Management Plan for all of the residents in the facility. This is typically a requirement of all licensing agencies. You should feel free to ask to for a copy of this plan. Because each child presents with their own unique needs, it will be important to also inquire further about how they individualize the Behavior Management Plan to meet the needs of each individual child. This is commonly referred to as an Individual Crisis Management Plan or something similar.

Make sure you ask about what are the typical positive incentives and consequences that your child would receive for positive and negative behaviors. Ask them to describe in detail their physical restraint and seclusion policies, including what model of intervention is used, how the staff are trained in that model, how often is the model used, and how are you made aware when these practices are used with your child. Typically parents and guardians are notified either by phone or email within 24 hours of a physical restraint being performed. You will want to know what their policy is.

16) Ask for examples of how previous crises were handled. Such as: violence outbreaks, physical injuries, sexual abuse, deaths of residents, runaways, alcohol/drug abuse, etc.
17) If a resident runs away or is hospitalized can they return to the facility?
18) Ask about the clinical component. What kind of treatment is provided to residents on a regular basis? How much? What type? What are the training and credentials of the personnel providing treatment? How will you be informed of your child's progress in treatment? Will you be able to talk to each individual member of your child's treatment team whenever you want or will your communication be limited to one team member of their choice and when will the communication occur? Is it required that parents attend weekly or monthly meetings on site to maintain your child's placement?
19) Where do all the residents go to school? Do you have a choice in the matter? Does your child? Is your home school district involved? If not, how will you be kept informed of your child's educational progress? How involved is the relationship between the residential staff and the school staff? Do they have regular meetings together to specifically share information and coordinate their efforts in assisting the residents' progress toward their goals?
20) Will you be allowed to make unannounced visits after your child is placed at this facility?
21) Is there a one-point contact for the parent/guardian for: clinical, residential, educational and financial/ICG administrative issues?
22) Specific questions concerning the Case Manager:
    a) How many clients are they responsible for? (average is 8-14)
    b) How often would my child typically have contact with this person? (one or more times per week depending on the child's treatment plan)
    c) Who is their backup for contact if they are sick or on vacation?
    d) Whom do they report to? (often a clinical director)
23) How are educational and clinical staffings integrated so that everyone is aware of and able to provide feedback about how your child is progressing on clinical treatment goals within the school setting?
24) What are the educational expectations within the residential program. Are they able to provide the educational services that are prescribed by your child's IEP? Is the school on-site or off-site, public or private, and what formal communication avenues are in place between the academic program and the residential treatment program. Who is responsible for talking with you regarding your child's academic progress?
25) What formal therapy services are provided? How often each day or week is your child going to participate in individual, group, and family therapy? What is the level of training and education of the therapist providing services? In what way does the program include evidence based best practices into their therapy programs? What can

you expect in terms of communication with the therapist(s) that work with your child?

26) Ask how the program includes parents, guardians, and families into the therapeutic programming being offered. Under what circumstances and how often are you asked to participate in or required to be involved with the program. What supports are you provided with as a parent? Can you volunteer on-site to help with your child or the program as a whole, such as family events?

After the visit:

1) Review the written material you were given. Does what you saw and heard match the program in the written material?
2) Were you comfortable with the staff you interacted with?
3) Were you comfortable with the other residents?
4) Do you feel you can trust these people?
5) Do you agree, or are you at least accepting, of their philosophy and the resulting policies and procedures? If not, keep looking. You won't feel better later. If you just have more questions, call and ask or return for another visit.

Evaluating services

Considerations with Mental Illness

Children with mental illnesses require different treatment approaches than are typically used for children with behavior and/or emotional disorders. These latter children are the majority in residential facilities and many fine facilities mainly provide care for them. Some, but not all, of these facilities will tell you that they don't have a program for MI children. This is a reason for serious concern. As the parent you should assess whether a facility’s therapy and behavior programs are appropriate for your child. Your ICG/SASS worker should be able to help you with this assessment.

Assessing Treatment for Mental Illness

The following are additional questions/considerations you should ask about during the initial visit.

1) Does the facility allow psychotropic medications to be administered to residents?
   Effective treatment of mental illness almost invariably starts with psychotropic medications. Once the child is stabilized behavior modifications can begin.

2) Are there psychiatrists on staff?
   Close communication/coordination between the psychiatrist and others at the facility is extremely important.

3) Will the psychiatrist attend the multi-disciplinary team meetings?
   These multi-disciplinary meetings plan the child's treatment. The psychiatrist is a key member of this team.

4) What is the frequency of multi-disciplinary team meetings to discuss your child's progress? Can you attend?
The Collaborative requires the residential treatment center to hold quarterly progress reviews for all children with an ICG. These meetings are expected to include the parent/guardian; and, when appropriate child participation is strongly encouraged. The ICG/SASS Worker and a Collaborative Case Manager will also be invited to participate in each quarterly staffing. The Collaborative will also require that the child, parent/guardian, and residential treatment provider staff complete the Ohio and Columbia Scales at each quarterly to assist in monitoring progress. Additionally, the residential treatment provider will be required to submit an Authorization Request for Residential Night Stays at the time of each quarterly staffing. This authorization is needed in order for the residential treatment providers to be paid for services rendered in the upcoming quarter and to maintain the students placement at that facility.. While the residential treatment center may not be able to accommodate everyone's schedule so that you can participate in person, you should expect that you will be given more than sufficient notice to adjust your schedule so that you can attend the meeting in-person or over the phone.. Ask who are the other professionals that regularly attend the meetings, it is most helpful to have broad representation within your child's treatment team.

5) Can you meet with the psychiatrist on a regular basis?
If staffings are less frequent or the psychiatrist doesn't attend them, more frequent (monthly) reassessments of medication can be effective.

6) Are behavior measurements captured, measured and reported? What is the frequency of this reporting?
Having quantitative information on the child's behavior is essential to treatment planning. The Collaborative requires that each quarter the child, parent/guardian, and residential treatment provider complete the Ohio and Columbia Scales. These scales provide a quick overview of the student's functioning. Residential treatment providers may collect other data on their own, so you will want to make sure you are aware of what data is being collected and what specifically it is demonstrating about your child.

7) Is the behavior data available to the psychiatrist in a timely fashion?
Sometimes data is only made available for quarterly reporting. If your child is experiencing frequent or intense psychiatric crises, it will be important to know how you can ensure that the psychiatrist be provided with more frequent and more detailed information in an effort to stabilize the situation.

8) Can treatment plans be individualized to include measures and interventions specific to the child? *Your child's comprehensive treatment plan needs to be individualized to include measures and interventions specific to the child. You will want to know how and when you will participate in the creation of the initial treatment plan and subsequent revisions of the plan as treatment progresses. Similarly, it will be important to ensure*

that your child is able and asked to participate in the creation of the initial treatment plan and subsequent revisions. This is essential for a child with mental illness as they and you need to feel empowered by the treatment process.

9) How will the facility plan for your child's transition to his home, school, community and, when appropriate, adulthood?
Planning for transition should begin at admission. Transition planning is essential to assure that progress made at the residential treatment facility is kept upon return home.

Parental responsibilities during placement

In addition to the Parent/Guardian responsibilities outlined in Section 135.30, the following are additional Parent/Guardian responsibilities from Section 135.90(f) of the Illinois Administrative Code:

1) Participation in and cooperation with the residential treatment facility is a requirement for the child's care, treatment and discharge to the family and community;
Active participation in and cooperation with the facility's requirements for the child's care, treatment, and discharge to the family and community. Maintain your own personal records of your participation, such as phone calls or meetings with your child and the staff working with your child, family therapy attendance, participation in school sponsored events, attendance to support groups related to your child's mental illness, home visiting experiences. You will be asked to report on these activities annually so keep track of them as you go along to make it easier when the time comes to share that information.;

2) Completion and submission of such forms and documents as may be required by the Collaborative;

3) The usual and customary costs of parenthood/guardianship, including:
   a) Clothing
   b) Medical and dental costs
   c) Personal allowance and incidentals
   d) Transportation costs, to and from the facility

   The residential treatment center may be able to assist in providing for some of these items if there is a demonstrated financial need. Check with your case manager or the business office of the program to find out if they provide need based assistance, this is particularly true in regards to subsidies for families to travel to participate in family therapy and to visit their child while in residential care.

3) Applying to the local education agency for the tuition costs of residential placement or making other arrangements to pay for such costs. A determination by the Department that an individual is eligible for the ICG/MI program is not binding on the local education agency in regards to special education services

Involvement in treatment

The ICG program recognizes the importance of all families in the lives of the children served by the grant. Family support is fundamental in a child achieving success within a residential treatment program and making a successful transition back home to the community and into adulthood. A child residentially placed will hopefully grow a great deal emotionally, socially, and behaviorally while in treatment. In order for this growth to be sustained, families likewise need to grow and change with their maturing and ever increasingly successful child. Therefore, it is a requirement of the ICG Program and the Collaborative that parents are actively participating in their child's treatment as decision makers and as individuals willing to change themselves. The residential treatment centers are required to report on each family's level of involvement in their children's care during each quarterly progress report and annual renewal request. Inaction does have a harmful effect on your child and may be a contributory factor in the annual renewal request being denied.

Family Therapy

The ICG program expects that you and your child participate in regularly scheduled, on-going family therapy while he/she is in residential placement. Most facilities provide this therapy as part of their program. The frequency will be determined through the treatment planning process. These family therapy sessions are intended to help you and your child deal with the many issues created by the child's illness. If frequent travel to the facility is impractical, these sessions can be done over the phone as determined to be clinically indicated by the residential treatment program.

Staffings

It is required by the Collaborative that your child's treatment will be reviewed on a quarterly basis by a multi-disciplinary team at a formal meeting called a "staffing". These treatment reviews should include broad representation from the child's treatment team, which includes you as a parent. It is also necessary for the Residential Treatment Center to submit a Reauthorization Request of Residential Night Stays each quarter for your child. This request is done in conjunction with the Staffings, which have a direct influence on treatment planning, monitoring, and continuation of residential funding.

Residential team meetings

If the residential facility allows it, you should attend the meetings of the residential staff when they discuss your child. You will learn a great deal about your child's progress and can help the staff better understand your child.

Psychiatric planning

Again, if the residential facility allows it, you should meet periodically with your child's psychiatrist to discuss his/her progress and medications. You can also help the psychiatrist by preparing a medication history showing what medication your child has been on, the dosage and the reason each was stopped.

Quarterly and Annual Reviews

Quarterly and Annual Reviews are required under Rule 135. The award dates determine when the Reviews are due. Parental residential quarterly reports are important but are not considered as part of the review process. This information assists the Collaborative's Clinical Care Managers with their perception of the functioning level of your child. The quarterly report include questions regarding level of functioning, compliance with rules and medications, school attendance, response to ICG services, clinical intervention, family involvement and crisis intervention.

Parental participation in the Annual Review is critical. It is important that this report be submitted in the allotted timeframe to avoid disruption of care to children in the program. Parents/guardians who are delinquent will receive a second notice to submit review materials. If the second notice is not complied with your child's funding is in jeopardy.

The Rule specifies that parents/guardians should be notified six weeks prior to the grant anniversary date to determine continuing eligibility for ICG funding. In order to make sure that the notices are giving parents/guardians and providers enough time to respond, the Collaborative will send notices sixteen weeks prior to the grant anniversary date. Annual Review material should be submitted to the Collaborative by the thirteenth week prior to the grant anniversary date.

Annual Reports will include: diagnoses, medication and symptoms targeted, therapeutic services and treatment plans.

Clinical Appeals

As a result of the Annual Review, a child may have his/her level of care changed (step-up or step-down). If the parent/guardian disagrees with the change in level of care, the parent/guardian may initiate a Secretary's Level of Appeal by writing: M. Kamran, M.D. c/o Illinois Mental Health Collaborative for Access and Choice, POB 06559, Chicago, IL 60606. Your SASS/ICG Worker can help you prepare this letter.

Financial Issues

There are possibly four (4) agencies or systems families will need to engage when considering residential placement. They are:

Social Security

Most children with a mental disability living in a residential environment **are** eligible for SSI benefits. After ninety (90) days parents should apply for SSI when the child is admitted to the chosen facility by going to the Social Security Office nearest your residence. The ICG/SASS

worker and/or residential provider can provide assistance with this process. These benefits will offset the cost of care that is paid by the Department. Either parent or facility can be made payee for the child. Specifics regarding this benefit should be discussed with the facility.

If your child is receiving SSI or SSA, these funds **must** be applied toward the cost of care at the residential facility. Again parent or facility can be the payee.

Education

Your local school district is responsible for education costs when your child is placed in a residential facility. You are urged to contact your school district as early as possible when you are considering residential placement. Illinois State regulations require that the local school district be notified ***before*** a child is placed. Failure to do so may jeopardize education payments and the residential placement.

Private Insurance

Your health care provider will be billed for medical and dental services. Additionally, all medications, psychiatric monitoring and medication administration may be billed. You are ***strongly*** encouraged to check with your insurance company about their requirements and whether pre-certification is needed.

Medicaid

Medicaid Rule 92R states that a youth who is in residential treatment for more than 90 days may be eligible for Medicaid. After 90 days, a youth is considered “living away from home” and the family income requirement is waived. All ICG providers are required to apply for Medicaid for each youth in order to maximize DHS’s reimbursements from the federal government.

Parents without medical coverage should personally apply for Medicaid through your local public aid office. Also parents with HMOs (only for kids going out of state) and parents/guardians whose medical benefits have been exhausted should apply for Medicaid.

Contact with Your Child

Visits

Every residential treatment facility has policies regarding visits. Some treatment centers encourage parent visiting, while others do not. Some facilities may provide housing for the parents to visit. Be sure to inquire as to what the visitation policies are in your child’s facility.

The extent of visits is usually determined by the child’s progress in treatment (child “earns” longer visits) and/or the particular needs of the child and the family. The best practice would be as much contact as possible if it doesn’t have detrimental effect on the child’s treatment or the relationship with the family. It is important that you and your child understand the decision making process and policies that govern visitation. It will be most helpful when visitation is

based upon clinical assessment of your child's functioning and their progress towards achieving their treatment plan goals.

Be wary of programs that have arbitrary visitation rules such as not allowing any visits, cancelling visits without clinical rationale, or even programs that allow visits regardless of the clinical functioning, as these approaches tend to undermine treatment progress. It is helpful to keep in mind, in addition to visits being a chance for your child and you to spend time together as a family, they are also a great way to see how your child is progressing and for you to practice new coping skills outside of the more intensely supportive residential treatment center.

Work with your child's treatment team to establish goals for each visit, no matter how small, and then report back to staff how you collectively did. As with your other activities, keep a log of how visits go, this will assist you in measuring treatment progress for yourself. You can share this information at Staffings and it would be extremely beneficial in your Annual Review Request reports, in which you have to describe your child's level of functioning.

Phone contact

Phone contact between the child and families is different in every facility. The frequency of phone calls is determined by your child's residential center. Some phone calls may be monitored, while others may be not. If the phone call is monitored, the residential treatment center is obligated to tell you that it is being monitored and provide you with a clinical rationale as to why that is necessary. Treatment centers cannot monitor calls or mail without express consent of you as the parent. The importance of consistent phone calls between you and your child and family members *must never be underestimated.* The messages of unconditional hope, love, trust and caring are conveyed from parent to child through consistent phone calls. You and your child will receive maximum benefit from these calls if you can consistently schedule them during at time when you can just focus on the phone call and when there are few distractions in the background.

Home Visits

More and more facilities are encouraging home visits for the child in residential care. Distance between the family and the facility can play a big part as to how frequent the visits home can be. In cases where the facility is further away, some facilities will help out with transportation. In the beginning of your child's stay at a residential treatment facility, the home visits may be less frequent. Home visits should help to explore treatment progress and prepare for return home. Be sure to inquire about the facility's policy on home visits before placing your child there.

Parental Involvement/Partnering with treatment facility

Parental involvement should be a part of all aspects of treatment. As the parent, you are ultimately responsible for your child's treatment. In each section outlined below, the parent's role will be identified.

Family Therapy

Family involvement is part of the requirement for continued funding for the ICG. Therefore it is

reasonable to expect that family therapy will be a part of treatment in all facilities. Parents/guardians should expect to see Family Therapy listed as an intervention on the Treatment Plan (explained below). When parents become involved will vary depending on the clinical needs of the child. Some facilities may want to wait for a period of time to assess the resident before initiating therapy while some may expect immediate involvement. In either case, parents/guardians should be clear as to the expectations of therapy and the desired goals. Feel free to question the clinicians in order to obtain these answers. For those programs that take a "wait and see" approach when the child is first in care, you may want to request to meet with whomever will be doing the family therapy without the child during this time. This would give you are chance to get acquainted, as they are with your child, before you begin meeting.

On an average, most facilities encourage family therapy once or twice a month. Much depends on the family involvement, accessibility to the facility, and the child's progress in treatment. It is the parent's responsibility to keep scheduled appointments or inform the clinician beforehand if they are unable to attend and why. Expect clinicians to report accurate parent participation. Example: if you have not been actively involved in therapy that will be reported to DHS.

Treatment Plan Development

Treatment Planning begins the minute the youth enters the treatment center or sometimes even before. The following assessments and time frames are specified for residential facilities (see accreditation and standards).

Assessment	Timeframe	Staff	Update
Admission Note and Initial Assessment	24 hours after admission	Case Manager or Clinician	Reevaluated quarterly in the ITP
Mental Health/Rehabilitative Assessment	Within 14 days	Multidisciplinary staff	Yearly
Individualized Treatment Plan (ITP)	Within 30 days	Clinician assigned	Monthly or quarterly

Admission Note and Initial Assessment.

This is not as detailed as the Treatment Plans to follow, but give the staffing team a guideline to begin treatment with. Parents/guardians will provide information for both. They usually will receive a copy of the Initial Assessment but not necessarily the Admission note. These should be available upon request.

Mental Health/Rehabilitative Assessment

This assessment is quite lengthy in nature and involves input from multidisciplinary staff. Parents/guardians should be involved in developing this assessment, but may only receive a copy

upon request. Parents/guardians are vital to the accurate and thorough completion of the Mental Health Assessment. The residential treatment center is expected to conduct a person-to-person interview, in your primary language, with you, and your child, in order to accomplish this. While much of the information involved may be reported in professional reports that you provide, in order to gain a full appreciation of your child's strengths, challenges, resiliency factors, a person-to-person exchange of information is essential.

Individualized Treatment Plan (ITP)

The ITP should include:

1. Estimated Length of Stay in Program (ELOS)
2. Permanency Goal
3. Discharge Plan
4. Overall Goal of Mental Health Treatment
5. Mental Health Goals to be Addressed
6. Identified Strengths and Assets
7. Diagnosis
8. Goals with Methods and Objectives and Outcomes
9. Evaluation of Progress Towards Achieving Outcomes
10. A listing of Prescribed Services and the staff Responsible for providing the services
11. A signature page. Signatures should include resident, clinician, and parent/guardian.

Parents should receive a copy of the completed ITP. It is important to know what your child's goals are, as well as how you can help them achieve these goals and support the treatment team.

Identifying clear and specific goals

Parents should expect to see clear goals and objectives on the ITP. If language used in these documents is confusing, contains jargon, or uses clinical language you are unfamiliar with, ask the clinician to explain this in more detail. Make sure your child understands what is expected of him in treatment and can also understand the ITP.

As mentioned above, many of the initial treatment goals will be determined by the Mental Health/Rehabilitative Assessment. Later goals will be determined by behaviors in programming and progress made on set goals. Some goals will be more generic in nature and address Case Management, Medical Care and Consultative Services. These are necessary to ensure accurate Medicaid billing. Other goals should address the reasons the resident was in need of residential treatment such as: anger management, aggression, peer interactions and family issues. Because family participation is essential to continue an ICG grant, family involvement/therapy should also be a part of the ITP.

Treatment Plan Review

Parents should expect their child's ITP to be reviewed on a quarterly basis by a multidisciplinary staffing. Some programs review progress on ITP's on a monthly basis. A multidisciplinary staffing should include the mental health professionals, the clinician, the teacher and, if possible, the psychiatrist. Unfortunately, psychiatrists usually are only at the facility for a set number of

hours, and are not always able to attend quarterly staffing. The clinician from the program should have regular contact with the psychiatrist and be able to report on and update the psychiatrist's treatment at the staffing. Parents should be invited to the quarterly staffing. They should feel free to ask questions and have input into treatment goals.

Case Management

The case manager should be easily accessible to the parent(s). Case management is an essential service that plays a critical role in the system of care for your child. It takes place in both residential and nonresidential programs and involves:

a) brokering service for individual children
b) advocating on their behalf
c) ensuring that an adequate treatment plan is developed and implemented
d) reviewing client progress
e) coordinating services
f) aggressive outreach to the child and family
g) working with them and other resources to ensure that all needed services and supports are in place

Many different providers and staff are involved with your child and their treatment. The case manager coordinates all aspects of treatment so that everyone works together in the best interest of the child. Typically the Case Manager takes an active role in all the key meetings concerning your child. These usually are weekly treatment team meetings, quarterly treatment planning meetings (staffings) and education planning (IEP) meetings. The case manager should be easily accessible to the parent(s).

A recent informal survey of residential providers found that the case management function is carried out in a range of ways. Therefore, it is important to understand, when interviewing residential facilities, how this function is handled and by whom.

There is an additional Case Manager assigned to your child from the Collaborative. The Collaborative Case Manager serves several roles, both clinically and administratively. Most importantly, they are an additional set of eyes and ears to help ensure your child is receiving the care they need and deserve. They also serve as an active participant in the on-going evaluation of progress, transition planning, and discharge determination. If you have any questions or concerns regarding your child's placement you can contact them in an effort to obtain answers or clarifications.

Parent Support Programs

Because having a child with a mental illness affects everyone within the family, it is customary for residential treatment programs to offer some form of parental support beyond family therapy; however, not all residential treatment programs do offer formal Parent Support Programs. If there is such a program, you are strongly encouraged to participate actively in the support program. You will gain a great deal from the experience and you will be able to help others similar to yourself navigate through this difficult period in your life. Remember there is strength in numbers. If parents want to develop a support program at the residential treatment center

where their child resides, they should discuss this with the Program Director. Parent Support Programs should not be prohibited or discouraged by the residential treatment center.

Discharge Planning

When parents/guardians place their child in a residential facility they understandably spend the first period of time after placement becoming comfortable with having the child away from home in the care of an institution. Initial discharge planning, the process of returning the child home, needs to begin soon after the child is residentially placed. Scientific outcome research supports the utilization of short-term placement and return to the home community over long term institutionalization of children with mental illness. Viewing discharge planning as a process that begins soon after placement and develops until the point that the child leaves the facility allows for a comprehensive plan to be put in place that meets the needs of the child and the family. Residential treatment centers are obliged under licensing rules and accreditation standards to begin assessing and planning for discharge at the time of admission. It might be most helpful to think of this initial discharge plan as the “ideal goal” that the multi-disciplinary team is working to accomplish. Because most children leave their residential program to return home, you are encouraged to be as active in the discharge planning and processes as soon as possible. Make sure the residential treatment center staff are aware of your concerns and limitations as well as any family and community strengths and mitigating circumstances that would facilitate a successful and smooth transition.

When a child leaves the residential facility they are eligible for transferring their ICG grant into a Community Based ICG, which will provide funding for community based services. It cannot be emphasized enough how important it is to work with your SASS agency before discharge to develop this plan. This will allow the necessary time to secure services and to get the funding transferred in a timely manner. This will help with a smoother transition to home. This involves parents working with the SASS agency to develop a plan. (See the section in this document on Utilizing the ICG in the Community).

There are three primary areas of need to address in a discharge plan for most children with mental illness, 1) mental health aftercare, 2) educational planning, and 3) community involvement; each area will be discussed below. There may also be additional needs individual to each child. With a minimum of 3 -6 months prior to discharge the residential treatment facility, the SASS agency and the parent should begin implementing a very specific plan to meet these needs. The child should not be discharged from the facility without a firm discharge plan that can be implemented as soon as the child returns home.

Mental Health Aftercare

Though the child may have had a very successful experience in residential placement they will almost always have a continued need for mental health care when they return home. Parents/guardians should expect and prepare to meet this need. Along with SASS and the treatment facility, parents should determine the resources available to meet any needs for psychiatric services, individual therapy, family therapy and therapeutic after school programming, as well as any other recommended mental health services. When children do not receive necessary mental health follow-up care there is a significant risk that they will regress

and lose the gains made while in placement. There are a variety of ways to fund mental health services in the community. Families should identify the resources they have available to meet these needs.

Children using community based ICGs are often eligible for therapeutic stabilization services as well. If this service is being requested, it should be done well in advance of the discharge (3 months or more) so that the SASS agency can begin to locate an appropriate worker for the child. Unfortunately, therapeutic stabilization workers are difficult to find in many areas of the state.

Educational and Vocational Planning

Education is an essential service to all children. In addition to providing learning opportunities, it allows for socialization and structuring the child's day. Children returning from residential placement have unique educational needs. They may have been away from their home school for many months, or even longer. Their learning abilities have changed, as have their classroom needs. Parents and the residential educators and clinicians must collaborate with the home school well in advance of discharge from the residential placement to assess the educational needs and put detailed plans and educational resources in place. There should not be a time lapse in education services when the child returns home. The SASS agency may be helpful in assisting parents with scheduling IEP meetings prior to the child's return from residential placement.

Community Involvement

One of the things parents report as being most helpful in integrating their child back home from residential placement is having a very well structured daily schedule. Children in residential placement have had daily schedules that are full of activity. When they return home many children are at a loss as how to structure their day and meet their needs for social contact and recreation. Prior to the children returning home, parents and SASS workers should have conversations with the child regarding their recreational interests, and resources should be obtained. Activities should be in place for the children to participate in at the time they return home. There should not be a lapse in time before activities are available when the child returns home.

Below is a timetable that identifies necessary discharge planning activities and the persons who should be responsible for them. As indicated, discharge planning requires good collaboration between the family, the residential placement, the home school, and the community mental health provider. If families wish to use the ICG for community services, the SASS agency must be involved. The table below indicates an ideal scenario. There may be instances when the timing varies somewhat; however, all services should be in place when the child leaves the residential facility.

TIME FRAME	RESPONSIBLE PARTY	ACTION
At RTC intake	Parents / RTC	Begin discussions about possible length of stay and needs upon return home
6 months prior to Discharge (D/C)	Parents	Contact SASS agency to discuss Community Based ICG options
3-4 months prior to D/C	Parents / RTC	Contact education system regarding educational needs, IEP, special education options
3 Months prior to D/C	Parents / SASS / RTC	Begin service planning / recruiting service providers/ find mental health providers/ identify recreation options/ Therapeutic Stab. (Respite) workers being recruited
3 Month Prior to D/C	Parents	Conversations with child about post D/C recreation interests
2 -3 month prior to D/C	Parents / RTC / SASS	Final D/C Date is determined
2 - 4 weeks prior to D/C	SASS / Parents	Completing Community ICG treatment certification forms. Family meets with respite worker to plan schedule / collaboration. Education plan is in place. Mental health appointments are scheduled for care in the home community
At D/C	SASS / RTC / Parents	Complete plan is in place. Education plan, mental health care, recreational activities, & respite begin
Immediately after D/C	SASS/Parents	Set backs will occur. Make adjustments as needed. Be flexible and hang in there. If a child can test the supports and they hold up, the child will gain confidence.

ICG Transition Services for Youth in Residential Placement

The transition service process is essentially the same for children receiving either community or residentially based services. If a child is in residential treatment the parent/guardian would expect more involvement from the residential provider; if using the ICG in the community, the SASS agency would be more involved. Please refer to more detailed information in the OVERVIEW section.

ICG Parents Group

The ICG Parents group is made up of parents who are interested in learning more about the ICG and services options from other parents. Through bimonthly meetings and other informal contacts parents can exchange information with others in similar situations. With only 400 or so ICG children statewide it is difficult to find people in the same situation as you are.

Group Objectives

- Provide information to parents
- Advocate for parents collectively and perhaps individually with legislature, agencies and providers to improve system
- Support for parents through sharing experiences and advice on approaches and resources

Meetings

- Meetings are held on the first Saturday of even-numbered months (February, April, etc.)
- Meetings are currently held in Oak Park Library, 834 Lake Street, Oak Park ILL. 60301. Parent/Guardian will be notified of the actual location. For further information you may e-mail Ray Connor at ray.connor@comcast.net
- Special Recreation associations run group activities for ICG youth during the meetings. These are fun social activities for our sons and daughters with ICG's. Detailed information and registration forms are available through your SASS agency. Your community ICG will normally cover the program fee for children living at home, and for children in residential treatment who are home on pass. **You must register through ICG/SASS, on-site registration are not accepted.**

Parents' Web Site

- The parents' group maintains a Group on Yahoo that has helpful information, links to useful web sites and a messaging facility.
- The group's web address is http://groups.yahoo.com/group/IllinoisICGParents
- To join the parents' Yahoo group, go to the above address and follow the instructions. If you don't already have a Yahoo ID you will need to create one. There is no charge for either the ID or for the group.

"Parent to Parent"

You can communicate with other parents by sending messages through the Yahoo group. You can do this by going to the group on the web and selecting Message and Post. You can also send email to IllinoisICGParents@yahoogroups.com**. Parent / Guardian maintain a confidential messaging facility you must be a member to use this feature.**

Taking Care of Yourself

Always remember to take quality time for yourself. Don't stop activities that make you feel good. Getting away and taking a vacation without your child is also a great way to enjoy some time with the other family members. Everyone in the family is affected by the illness, so it is important to enjoy life with the other family members as much as possible.

Reducing stress will help you enjoy your life. There are many ways to reduce stress. Exercise, go out to dinner, read, spend time with friends, seek out a good therapist, talk to your family and friends about the illness, educate yourself to help relieve the anxiety of the unknown, and don't isolate yourself.

Children/Adolescents living with mental illness brings so many ups and downs into your life. Try to enjoy and be positive during the up times, and look for your support during the down times.

TAKE CARE and….

1) be gentle to yourself,
2) remind yourself that you are a loving helper, not a magician,
3) find a place where you can be a hermit – use it every day – or when you need to.
4) Learn to give support, praise and encouragement to those about you – and learn to accept it return.
5) Remember that in the light of all the pain we see around us, we are bound to feel helpless at times. We need to be able to admit this without shame. Just in caring and in being there, we are doing something important.
6) Learn to vary your routine often and to change your tasks whenever possible.
7) On your way home from work, focus on one good thing that happened during the day.
8) Become a resource to yourself! Be creative and open to new approaches to old things.
9) Use the support you give to others or a 'buddy' system regularly. Use these as a support, for reassurance and to redirect yourself
10) Find support groups both on the Internet and in the community.
11) Above all else – learn to laugh and to play.

References: "How to Heal Yourself: The Curing Power of Hope, Joy, and Inner Peace." From Peace, Love and Healing, by Bernie S. Siegel, Harper and Row, 1989.

Advocacy

One of the best definitions of advocacy comes from Eleanor Roosevelt. "You must do the things you think you cannot do." While we are facing the stigma and shame that still surrounds mental illness, we are constantly being met by many challenges. We have all had to break through boundaries of fear and convention to help our family member. We have all felt the discrimination that exists against people with brain disorders.

Advocacy is a type of problem solving designed to protect personal rights, and to insure a dignified existence. Self-advocacy involves advocating for oneself, while individual advocacy involves advocating for another.

Advocacy skills can help you avoid or solve problem with family, doctors and associates. They can help you obtain reasonable and necessary accommodations in both public and private settings.

Then, there may be times when your rights to humane treatment and dignified existence will have been ignored or denied. Advocacy skills can help you identify, analyze and make informed decisions concerning such choices. Regular practice of advocacy skills will empower you to gain more control over your life and your loved one.

You should expect to have a relationship with the professionals caring for your child that allows you to work as equals with a goal of making the best possible decisions for your child. You are the expert on your child; mental health professionals are experts on mental health care and resources. The knowledge that parents and professionals each bring to the table is different, but each is essential. Ultimately, parents have the responsibility to make decisions on their child's care, hopefully this can be done with the help of a trusting relationship with mental health professionals. You can get the best care for your child by being friendly-yet firm, assertive-not angry and persistent-not pushy. You are your child's most important advocate.

The more we speak up and speak out, the more we will help our children and other children with mental illness. There is a tremendous need for parents to advocate for increased mental health services with both local and national organizations. Be involved at the level that is appropriate for you.

Tips for Parent/Guardian Participation in Meetings *

BE POSITIVE

Go to the meetings with a positive attitude

BE PREPARED

Go to the meetings with specific ideas, suggestions and questions to ask

BE DIRECT

Speak clearly and avoid vague statements or charges. If you have specific concerns, bring them up and let staff respond to your concerns.

BE CONFIDENT

Do not be intimidated. If terms or concepts are presented that you do not understand, ask for clarification.

BE CALM

Remain in control of your feelings. A meeting can plan more effectively when all participants are calm and no member is under attack.

BE INVOLVED

Take an equal and active role in the meeting. You may have information that is important - do not be afraid to ask questions, to disagree with suggestions or to expect the team to treat you with respect.

*from A Parents' Guide (Revised 1998) The Educational Rights of Students with Disabilities

Transition Timeline for Children and Adolescents with Disabilities

This time line was developed by the Division of Rehabilitation Services (DRS) January 2002. The time line suggests a wide variety of tasks that students, parents, educators and community providers should consider throughout the transition process. It is intended as a guide and checklist to help students with all types of disabilities get the most out of their education and make a successful transition into adult life.

ELEMENTARY YEARS

Child

- Participates in career awareness opportunities
- Becomes aware of and uses word processor/computer.
- Has work chores at home

Parents

- Participate in NEXT STEP training
- Bring the child to IEP meetings
- Emphasizes good study habits, time management, and organizational skills.
- Stress personal and health care skills at home, shopping patterns, eating out in restaurants and money skills.
- Identify acceptable dress and behaviors in the community
- Let child make choices

School and Educators

- Provide parents with information about how they can prepare their child for transition and adult life.
- Emphasizes good study habits, time management, and organizational skills.
- Introduce parents and students to concept of accommodations for persons with disabilities/disability awareness/self advocacy.
- Encourage parents to bring children to IEP meetings.

FOUR TO FIVE YEARS BEFORE LEAVING SCHOOL (AGES 12-14)

Student

- Participates in vocational career assessments.
- Learns and begins to use available public transportation.
- Begins job shadowing opportunities and continues each year with emphasis on career planning
- Begins exploring future career goals for transition areas.
- Begins formal career counseling.

- Explores service learning opportunities in community and school.

Educators
- Introduce and discuss transition process with parents and students.
- Plan on transition services being incorporated into the IEP beginning at age 14.
- Develop transition component of the IEP and update annually with linkage to individual career plan (ICP) if one exists.
- Develop strategies to increase responsibilities and independence at home and community.
- Discuss work-training opportunities in school.
- Obtain parental consent so appropriate adult agency representative can be involved, contacted, and /or information shared through transition years as needed.
- Provide formal career counseling
- Encourage involvement in extra curricular activities

Parents and Educators
- Stress job development training for students (i.e. Punctuality, neatness, getting along).
- Stress self-care skills and making choices.
- Give students opportunities to make choices and own decisions.
- Develop a transition file/portfolio. Encourage students to request appropriate accommodations in school, home, work and community environments.
- Become familiar with local case service coordination agencies.
- Explore service learning opportunities in community and school.

TWO TO THREE YEARS BEFORE LEAVING SCHOOL (AGES 15-17)

Students
- Begin work/training experiences in school and community.
- Obtain summer employment and volunteer experiences. Use IEP to assist students in refining their future goals in all transition areas and selecting performance measures within graduation standards that meet Illinois learning standards.
- Select courses to explore career interests and skills based on career goals.
- Participate in extra-curricular activities and community organizations, and make connections with Centers for Independent Living.
- Obtain personal ID card and keep copies of work- related documents available: Social Security Card, Birth Certificate, work permits.
- Obtain drivers training and license as appropriate.
- Take ACT test junior year as part of Prairie State tests.
- With parents' assistance, begin collecting information about institutions of higher education if post-secondary education is a goal.

Parents and Educators

- Encourage students to select courses to pursue career interests and develop skills based on career goals, including vocational education.
- Assist student to develop first resume.
- Develop transportation/mobility strategies in IEP plan.
- Assess need for assistive technology for adult life in career plan.
- Discuss guardianship or emancipation.
- Involve other community service agencies, as appropriate.
- Give students opportunities to make choices and own decisions.

Educators

- Assist parents and students to understand their legal rights under the American with Disabilities Act and Section 504 of the Rehabilitation Act, especially as related to their legal right to accommodations. Link to Center for Independent Living if one is available.
- Provide students and parents specific information about available adult services based on transition goals.
- Learn about Office of Rehabilitation Services (no case needed).
- Encourage families to visit local housing and explore independent living options.
- Refine and decide, with the student, future adult goals in all transition areas (employment, post secondary education, and community living).l
- Identify local providers and services for supports and housing.
- Update or request needed vocational evaluations.

ONE YEAR BEFORE LEAVING SCHOOL (AGES 18-19)

Students, with Parents' Support

- Investigate Social Security benefits, Ticket to Work, or benefits analysis.
- Research possible independent living options and become familiar with referral processes.
- Identify residential options and apply if needed.
- Review health insurance coverage and, if necessary, contact the Division of Specialized Care for Children (DSCC).
- Identify a desired job upon graduation.
- Apply for college and other educational training programs and scholarships.
- Formalize relationships with Office Rehabilitation Services and open case for employment.
- Develop resume and portfolio.
- Visit local One Stop and explore resources.
- Register to vote; male students should register with Selective Service.
- Complete transition to employment, further education or training, and community living, and confirm arrangements.
- Review Medicaid or Health Benefits for Workers with Disabilities program.

Parents/Educators

- Assist students and families in applying for post school support services (i.e., rehabilitation services, social services, health services, developmental disabilities services, social security, pass plans,).
- Begin the process for legal guardianship.

Related Websites:

One- Stop Career Centers7
www.ides.state.il.us

Illinois Network of Centers for Independent Living
http://incil.org
1-800-587-1227

Illinois Community College Board (ICCB)
www.ICCB.state.il.org.
1-217-785-0123

Illinois State Board of Education
Special Education/Education -to -Career
www.isbe.state.il.us/speced/parent-trainiginfo.htm

The National Information Centers for Children and Youth with Disabilities (NICHCY)
http://www.nichcy.org/ or 1-800-695-0285

Appendix 1 - Acronyms

ADA	American with Disabilities Act
ADD	Attention Deficit Disorder
ADHD	Attention Deficit with Hyperactivity Disorder
BD	Behavior Disordered
C&A	Child and Adolescent
DCFS	Department of Children and Family Services
DHS	Department of Human Services
ED	Emotionally Disturbed
ESY	Extended School Year
FAPE	Free Appropriate Public Education
FERPA	Family Education Rights and Privacy Act
FRCD	Family Resource Center on Disabilities
ICG	Individual Care Grant
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Program
ISBE	Illinois State Board of Education
ITP	Individualized Treatment Plan
LCSW	Licensed Clinical Social Worker
LD	Learning Disabled
LEA	Local Education Agency
LSW	Licensed Social Worker
NAMI	National Alliance for the Mentally Ill
OCD	Obsessive Compulsive Disorder
ODD	Oppositional Defiant Disorder
OMH	Office of Mental Health (part of DHS)
ORS	Office of Rehabilitation Services (part of DHS)
PDD	Pervasive Developmental Disabilities
PTSD	Post Traumatic Stress Disorder
RTC	Residential Treatment Center
SASS	Screening, Assessment, Support Services
STEP	Secondary Transition Employment Program
UIR	Unusual Incident Reporting Forms

Appendix 2 - Definitions

Aging Out A phrase used in mental health to describe youth who, based solely on age, will no longer be eligible for child and adolescent mental health services when they reach the age of 18 years. Despite educational status, the young adult must have the linkage process started with the adult mental health programs in the community in order to bridge him/her to the appropriate services .The ICG Program has an "Aging Out Protocol" to address this issue. It is suggested that this process start 12 months before the youth's 18th birthday.

Americans with Disabilities Act (ADA) The ADA, passed in 1990, gives civil rights protections to individuals with disabilities. More specifically, it mandates equal opportunity for person with disabilities in employment, public accommodations, transportation, state and local government services, and telecommunications.

Children Are individuals under 18 years of age.

Days Refer to calendar days.

Department Refers to The Department of Human Services

Discharge planning Critical planning steps needed in order to prepare the child, the family, the school and SASS agency for discharge from a residential treatment facility within a designated time frame. When done correctly, community supports/structure should be in place before the child returns to the community (the ICG/SASS worker need to be a part of discharge planning in order to have the appropriate school ready to receive the child; recreational activities in place; psychiatric/therapists appointments made; medication needs attended to). The child and family need to have time alloted to discuss their fears about discharge and need to have home visits regularly in order to ease fears. Having these supports in place greatly increase the chances of a successful discharge from residential to community.

Due Process -A legal term that assures that persons with disabilities have the right to challenge any decision made on their behalf.

Due Process Hearing A formal meeting held to settle disagreements between parents and schools in a way that is fair to the student, the parents and the school. An impartial hearing officer runs the meeting. A hearing can be requested at any time for any reason and cannot be denied by the school district.

FAPE-Free Appropriate Public Education The words used in the federal law (IDEA) to describe the right of a student with disabilities to receive special education and related services which will meet his/her individual learning needs, at no cost to the parents.

Family Resource Developers are parents of youth with serious emotional disturbances who have been trained to mentor parents of youth with similar difficulties. They are affiliated with the SASS programs.

Guardian The court-appointed guardian of the person and/or estate under the Probate Act of 1975 [755 ILCS 5].

Intensive Home Based Services Programs that are capable of providing individual and family services within the home setting. Alternative settings will be located should the family not desire this or it's not clinically indicated.

Licensed Social Worker (LSW) Person has graduated from either a Master's degree program in social work or graduated with a bachelor's degree in social work and has at least 3 years of supervised professional experience as well as successful completion of the professional exam.

Licensed Clinical Social Worker (LCSW) Person has either graduated from a Doctoral program in Social Work and has 2000 hours of supervised clinical professional experience or graduated from a Master's degree program in Social Work and has had 3000 hours of supervised clinical experience. Successful completion of the professional exam and licensure under the Clinical Social Work and Social Work Practice Act is also required. A Social Worker does not do psychological testing or prescribe medications.

Licensed Clinical Psychologist A person who is a graduate of a recognized Doctoral program; has 3500 hours of supervised clinical experience as well as successful completion of the professional exam and is licensed under the Clinical Psychological Licensing Act. A psychologist does psychological testing but cannot prescribe medication.

A **School Psychologist** has different professional training, is not required to have a Doctoral degree and has a School Service Personnel certificate with an endorsement of School Psychologist issued through the Illinois State Board of Education and the State Teacher Certification. The Scope of their job duties is outlined in "School Psychological Services".

"**Life domains**" Refers to the major areas of functioning in the child's life that may be impaired by the child's mental illness.

Mediation process If you have unresolved concerns regarding the appropriateness of the special education program and related services provided to your child, you may request mediation. Mediation is a voluntary process in which both parents and school district personnel meet to resolve disputes with the help of a trained mediator. In mediation, both you and the local school district are brought together to discuss and consider alternative solutions to the issue, your child's capabilities, and the concerns and problems expressed by the other party. Mediation is designed to resolve issues without going to the often more expensive and more formal due process hearing. This service is provided by the state at no cost to you or the local school district. If you want to request a mediation or learn more about the mediation process, you may contact the mediation coordinator, Division of Special Education Compliance, Illinois State Board of Education, at 217-782-5589

Medical Doctor or Family Practitioner Able to prescribe psychotropic medications but residency is not focused in Psychiatry or Behavioral Health. This may be all that is available to some families with HMO's. Good first choice if it's a simple clinical issue. Clinical therapy is

strongly recommended as an adjunct to psychotropic medication and insurance will usually pay for this.

Network An organizational unit of the Department's Office of Mental Health responsible for administering State funds for mental health services within a geographically defined area and for organizing a network of mental health services through public and private providers.

Division of Rehabilitation Services (DRS) This is the lead agency within the Illinois Department of Human Services, which provides services to people with all types of disabilities. Their goal is to help people achieve self-sufficiency and to live independently.

Psychiatrist - Board Eligible A medical doctor who has completed an accredited adult psychiatry Residency program and should have a residency diploma. Doctor has met the requirements to sit for the exam but has not yet passed the exams.

Psychiatrist - Board Certified: Doctor has passed rigorous Board exams. This achievement comes with a certificate that is recognized nationwide. Doctor must be Board certified in adult psychiatry before sitting for Board certification in C&A

> ***Child trained Psychiatrist** (can be either Board eligible or Board certified in adult psychiatry - see above). Doctor had additional training in an accredited child fellowship program and will have a fellowship certificate on completion, but has not yet passed the Child & Adolescent Boards.
> ***Board Certified in Child/Adolescent Psychiatry:** Doctor has passed rigorous C&A Board exams. This Board certification will have another certificate also recognized nationwide. Doctor must be Board certified in adult psychiatry before she can sit for Board certification in C&A
> ***Adolescent Board Certified**: Person would be either Board eligible in adult or board certified in adult. No formal training in an accredited fellowship. Person passed an additional test and will have a Board certificate. Some states do not recognize this certification because it is not as well controlled.

Recovery of Attorney Fees The Handicapped Children's Protection Act of 1986 provides for the recovery of attorney fees. A parent who prevails in either a hearing or court action may recover reasonable attorney fees subject to limitations. It is advisable that prior to proceeding to a hearing, you thoroughly discuss with an attorney the question of cost and the applicability of this law.

Reevaluation An assessment that occurs every three years, or more if needed to determine continued eligibility for special education.

Region An organizational unit of the Department's Division of Mental Health responsible for administering State funds for mental health services within a geographically defined area and for organizing a network of mental health services through public and private providers

Secondary Transition Employment Program (STEP) STEP is designed for youth in high school, ages 14-21, who have significant disabilities. Individuals participating in the program are

usually participants in special education programs in high school. DHS services include job shadowing, job coaching, classroom instruction, job placement, independent living skills training, community skills training, on -the-job evaluation/training and work experience (both school and community based).

Section 504 of the Rehabilitation Act The first federal Civil Rights Law to protect the rights of people with disabilities in federally funded programs in all areas: education, vocational education, housing, employment, transportation, and civil rights.

Screening, Assessment, Support Services (SASS) This comprehensive approach to child & adolescent mental health crisis services provides not only immediate crisis interventions to the targeted population but also an array of intensive services including: assisting ICG families; in home supports; case management with linkages to other supports and services; rehabilitation stabilization, and transitional care back to the home setting if the child/youth has been psychiatrically hospitalized or residentially placed. All communities in Illinois are served by a SASS program through the designated local mental health agency in your area.

A System of Care for Children and Youth with Severe Emotional Disturbances
This is the model the State of Illinois has been using to reform children's mental health over the last decade.

- A system of care is a comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of children and adolescents with severe emotional disturbances and their families.
- Additionally, the term "system of care" is used to emphasize the multiple needs of children with emotional disturbances and the importance of establishing effective linkages across child-caring agencies and systems. It is recognized that children with severe emotional disturbances require a variety of services that cut across agency boundaries.

Transition Services (Education and DRS working together) For each student who will reach the age of 14 during the school year and for younger students if determined appropriate, the IEP must document a statement of transition service needs that focus on the student's course of study. Courses should reflect the student's preferences and interests and address post-school outcomes.

For students who will reach the age of 14 1/2 during the school year and for younger students if determined appropriate, the following must be documented in the IEP:

- A statement of goals for life after graduation from high school in the areas of employment, post secondary education, and community living alternatives;
- A statement of any needed transition services that are in addition to the current education program;
- A statement of each participating agency's responsibilities for providing needed services.

It is **EXTREMELY IMPORTANT** to know that any eligible child who requires continued special education services in order to "facilitate his or her integration into society" shall continue to be eligible for services through the school year during which the student turns 21. However, if

your child is graduated with a regular high school diploma or its equivalent before the age of 21, this provision of FAPE is not required and the school is under no further legal obligation to provide free education or transition services for your child.

Transition Supports into Adult Service Delivery System (Mental Health and DRS) - As part of all individualized care planning, attention is paid to the community living skills and career track of adolescents with serious emotional disturbances. This is especially true for adolescents served through the ICG program where youth in highly restrictive settings require extensive, intensive planning for successful transition to adulthood. An Aging-Out Protocol has been implemented by the ICG to assist youth and their families in the transition from child to adult services and from institutional to community living.

Young adults- Individuals 18 through 21 years of age

Young Adult Support Services- Time limited funding for young adults to cover costs of services and supports, not included under other programs for which the person may be eligible, to aid the young adult in his or her transition to community living. These funds can be applied to the costs of a supported living arrangement or other appropriate transitional services that help to integrate the young adult into his or her adult roles in the community.

Appendix 3 - References/Resources

FAMILY RESOURCE CENTER ON DISABILITIES (FRCD)
20 E. Jackson Blvd.
Chicago, IL 60604
312.939.3513
800.952.4199

WHO THEY ARE:
A coalition of parent and professional organizations

FCRD PUBLICATIONS:
The Family Resource Center on Disabilities publishes notable training manuals and pamphlets, which are distributed nationally.

Training Manuals
- How To Get Services by Being Assertive
  A 100 page manual that demonstrates positive assertiveness techniques for staffing, IEP meetings, due process hearing, and other special education meetings.
- How to Organize an Effective Parent/Advocacy Group and Move Bureaucracies
  A 100 page handbook that gives step by step directions on how to organize a parent group from scratch-and actively involve members to effect positive changes to improve services
- Special Education Manual
  A 160-page manual that provides up to date federal and state special education rules under one convenient cover.

Pamphlets (available in English and Spanish)
- Does Your Child Have Special Education Needs?
- How to Participate Effectively in Your Child's IEP Meeting
- How to Prepare for a Successful Due Process Hearing
- Tax Guide for Parents (Available in English)
- Your child's School Records

WHAT THEY DO:
- Information and referral services (Answers more than 8,000 phone & mail requests per year)
- Family support services
- Transition services (funded by US Department of Education, Office of Special Education programs)
- Special education rights training- (free)
- Parent to Parent Training Project (funded by US Department of Education, Office of Special Education programs)
- Outreach to underserved families

The FRCD states that advocacy has become an "in" word, an "in" activity, unlike the 60's when calling yourself an advocate was like calling yourself a radical. Today, advocacy is not only

acceptable; it is often supported by federal and state government agencies

Websites

System of Care website has information about LANs and the E/BD (Emotional/Behavioral Disorder) Network.
www.systemofcareillinois.com

Equipped for Equality is a federally funded legal advocacy group.
www.equipforequality.org

Website where you can access a list of non-public approved schools through ISBE
www.hbug.k12.il.us

Family Support Network is a nationwide information and resource directory.
www.familysupportamerica.org

Illinois State Board of Education website
www.isbe.net

Department of Human Services/Division of Rehabilitation Services website that gives information about Transition Services
www.state.il.us/agency/dhs/rsnp.html

Center for Mental Health Services/Child and Adolescent Mental Health
http://www.mentalhealth.org/child/childhealth.asp

Surgeon General's Conference on Children's Mental Health
http://www.surgeongeneral.gov/topics/cmh/childreport.htm

National Federation of Families for Children's Mental Health
http://www.ffcmh.org/

Portland Research and Training Center
http://www.rtc.pdx.edu/

Bazelon Center for Mental Health Law
http://www.bazelon.org/

NAMI
http://www.nami.org

Global Alliance of Mental Illness Advocacy Networks - committed to the empowerment of consumers to seek appropriate professional healthcare treatment that will improve the quality of life of patients, their families, and their communities.
http://www.gamian.com

Companion Resources
http://www.cresources.org/mental

Treatment Advocacy Center
http://www.psychlaws.org

Federal Money Retriever - Government grants and loans: Protection and Advocacy for Individuals with mental illness
http://www.fedmoney.com/grants/93128.htm

National Mental Health Association - Advocacy, education and services
http://www.nmha.org

Transition Services

The Web site addresses listed below were compiled by The Technical Assistance about Transition and the Rehabilitation Act (TATRA). A wealth of information related to transition and rehabilitation issues can be found at these web sites. If you do not have ready access to a personal computer to reach these web sites on the Internet, simply take this list to your local public library and ask a library staff member for help in using the computer.

ADA Technical Assistance Program: http://www.adata.org

Assistive Technology Funding and Systems Change Project:
http://www.ucpa.org/html/innovative/atfsc/index.html

Department of Human Services/Division of Rehabilitation Services High School Counselors
http://www.dhs.state.il.us

National Clearinghouse of Rehabilitation Training Materials:
http://www.nchrtm.okstate.edu/index_3.html

National Information Center for Children and Youth with Disabilities: http://www.nichcy.org

National Transition Alliance: http://www.dssc.org/nta/html/index_2.htm

National Transition Institute: http://www.ed.uiuc.edu/coe/sped/tri/institute.html

National Transition Network: http://www.ici.coled.umn.edu/ntn

Office of Special Education Programs: http://www.ed.gov./offices/OSERS/OSEP/index.html

Office of Special Education and Rehabilitative Services: http://www.ed.gov./offices/OSERS

Project Tech Link-Linking Educators and Parents to Transition Best Practices through Computer Technology: http://www.vcu.edu/rrtcweb/techlink/index

Rehabilitation Services Administration: http://www.ed.gov/offices/OSERS/RSA

School to Work Outreach Project: http://www.ici.coled.umn.edu/schooltowork/

Serving Youth with Disabilities within School-to-Work Systems (fact

sheet):http://www.stw.ed.gov./factsht/bull0696.htm

TATRA (Technical Assistance about Transition and the Rehabilitation Act) Project: http://www.pacer.org/tatra

Technical Assistance Alliance for Parent Centers: http://www.taalliance.org/

Books/Manuals

Illinois Administrative Code

TITLE 59: MENTAL HEALTH
CHAPTER I: DEPARTMENT OF HUMAN SERVICES
PART 135 INDIVIDUAL CARE GRANTS FOR MENTALLY ILL CHILDREN
http://www.ilga.gov/commission/jcar/admincode/059/05900135sections.html

TITLE 89: SOCIAL SERVICES
CHAPTER III: DEPARTMENT OF CHILDREN AND FAMILY SERVICES
SUBCHAPTER d: LICENSING ADMINISTRATION
PART 384 BEHAVIOR TREATMENT IN RESIDENTIAL CHILD CARE FACILITIES
http://www.ilga.gov/commission/jcar/admincode/089/08900384sections.html"The purpose of this Part is to explain acceptable behavior treatment techniques and to assure that these techniques are used only under controlled conditions by appropriately trained personnel. This Part will also identify limitations and restrictions on specific behavior treatment techniques related to crisis prevention, behavior intervention, and behavior management."

Parent Guide - Educational Rights and Responsibilities: Understanding Special Education in Illinois, - published by Illinois State Board of Education

http://www.isbe.net/spec-ed/pdfs/parent_guide_english.pdf
You may also get a copy of the guide by calling the ISBE Information Center at 1-866-262-6663.

Peace, Love and Healing: Body mind Communication and the Path to Self-Healing: An Exploration, Bernie S. Siegel, Harper and Row, 1989.
ISBN-13: 978-0060917050

Phone Numbers

1. **Illinois Mental Health Collaborative For Access and Choice**
   PO Box 06559
   Chicago, IL 60606
   Phone **773-794-4884**
   TTY: **(866) 880-4459** Fax: **(866) 928-7177**

2. Illinois Department of Human Services (Client Assistance) 800-843-6154
   TTY 800-447-6404

3. Division of Rehabilitation. Services - (Client Assistance) 1-800-641-3929

4. Illinois State Board of Education (Client Assistance) 1-866-262-6663
   Illinois State Board of Education Information Center 1-217-782-6601

Appendix 4 - Acknowledgements

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