

RESIDENTIAL TREATMENT FOR YOUTH WITH MENTAL HEALTH NEEDS



A GUIDE FOR PARENTS
AND GUARDIANS



“Your present circumstances don't determine where you can go; they merely determine where you start.”

—Nido Qubein



Residential Treatment for Youth with Mental Health Needs:

A Guide for Parents and Guardians

The Illinois Children's Mental Health Partnership
Residential Treatment Work Group



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The Illinois Children's Mental Health Partnership (ICMHP) Residential Treatment Work Group, under the direction of Ray Connor and Kara Teeple, assumed the task of the Guide with enthusiasm. Ray Connor, as co-chair of the Work Group and as the chair of the ICG Parents Group, gave tirelessly of his time and knowledge to ensure the success of this endeavor. Kara Teeple and other work group members provided expertise grounded in day-to-day realities of work with children and youths involved in residential treatment and mental health systems. The Guide was edited by Jean Davidson Meister.



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“It was just so difficult to decide to place our daughter in an RTC (Residential Treatment Center). It felt like we were admitting failure and we couldn’t handle the situation. We were completely overwhelmed. But when she arrived at the RTC, I could see how this was a good place for her.”
—Carlos



Introduction

The decision to place a child in a residential facility is one of the most difficult and most important choices that you can make for your child. It is a time of stress and upheaval for everyone involved—the child, siblings, parents, and guardians.

Treatment works. Early, intensive care can make a lifelong difference for youths with mental illness. Treatment can help struggling youths learn to manage their illness, succeed in school, improve relationships, and build resilience. Treatment works best when there is a partnership between the child, family, physicians, and therapists.

This guide provides information to help you through each step of the residential placement process. Residential treatment offers safety, structure, therapy, and round-the-clock supervision that families are not equipped to provide. Residential treatment also can benefit your family. Often, parents and siblings have lived through years of crises, and a residential placement provides time, space, and help to heal.

Choosing a residential placement does not mean you have failed or given up on your child. It does not mean you no longer have a say in your child's life. As long as you are legal guardian, you have a right to be informed and to make decisions about your child. With such a complex system, it is possible for parents to be given misinforma-

tion during the decision-making process. This Handbook provides the authors' best understanding of the system and the process.

You remain vitally important in your child's life and treatment. You know your child better than anyone else. You best understand your child's history, strengths, and challenges; what soothes or stresses your child; and what activities your child enjoys most. These are all important factors to weigh when choosing care. Additionally, it is important to keep in mind that every family is unique, with different cultural, racial, ethnic, and economic backgrounds; and treatment choices need to respect and support these differences.

You may feel overwhelmed and isolated. Relatives, friends, and neighbors often do not understand what your family is going through, because they have never experienced these extraordinary challenges. It can help to talk with others who understand. Consider joining a support group in your community, through your child's residential placement, or online.

This is a difficult journey and there will be setbacks. Treatment and support can help you and your family to navigate the road ahead. (See Appendix A, pg. 35, for a checklist to help you get started)

Overview: About this Guide

The Purpose of this Guide is to:

- Provide information to parents and guardians about the residential treatment system
- Encourage parents and guardians to be informed partners in their child's treatment
- Support children and families as they transition between residential and community services

The Children's Mental Health Act of 2003 marked a new beginning for the healthy development of children and families in Illinois. The CMH Act included provisions to improve access to services for children with mental health needs and their families. The Illinois Children's Mental Health Partnership (ICMHP), which was created by the CMH Act, promotes healthy social and emotional development, early intervention, prevention, and treatment for children and youths.

Residential Treatment for Youth with Mental Health Needs: A Guide for Parents and Guardians was developed through the ICMHP by a group that included parents of youths with mental illness, mental health providers, residential treatment providers, and education and child welfare experts.

The goal of this Guide is to empower parents and guardians by providing reliable information to help them to make the best decisions for their child and family. A wide range of treatment options is available, from community-based services to residential placement. While not every community offers the identical services and access, community services can enable many children to function well and remain in their homes. Residential treatment is needed in some cases of severe illness. The safety of your child, family, and community must be the first priority.

This guide can help you access services, learn about funding and placement options, ask the right questions about residential treatment centers, understand your rights and responsibilities, and take part in transition and discharge planning. There is also information about family therapy, support groups, and other assistance.

“When my son put his fist through a window, I didn’t know who to call for help. When you are considering residential placement, things are the very worst they can be.”

—Ron



Emergency Help and Screening

**CARES is available 24 hours a day, seven days a week at: 800-345-9049
TTY 800-905-9645**

CARES covers:

- Children under 18 who are eligible for public funding for psychiatric services.
- Children under 18 whose private insurance does not cover mental health treatment, or whose coverage is exhausted.
- Children under 21 enrolled in All Kids and other public programs, and any person for whom DCFS has legal responsibility.

To find your community mental health provider, call 312-814-5050 or visit www.mentalhealthillinois.org.

Youth with mental illness can become very angry, sad, or even suicidal. It is important to plan what to do in an emergency. Make sure emergency phone numbers are easily accessible.

If your child has a crisis and you can't help him or her calm down, a 24-hour service called CARES can come to your child. You can call CARES at 800-345-9049 or 773-523-4504 (TTY). CARES stands for Crisis and Referral Entry Services.

CARES will send a crisis worker to your house to evaluate your child. The crisis worker, from a program called SASS, will talk with you and your child. SASS stands for Screening, Assessment and Support Services. Keep the CARES phone number where you can find it quickly in an emergency.

A SASS worker will assess your child before any hospitalization, and will link your family to services and supports. SASS will work with you for at least 90 days to ensure that your child gets the mental health care he or she needs. If your child is hospitalized, SASS also will help to plan services to assist your child and family when your child returns home.

The goal of SASS is to provide services to help youths return to the same level of functioning and the same living arrangement as before the mental health crisis.

The SASS worker also will offer support and services to aid parents or guardians. In addition, SASS workers provide ongoing services and supports for youths who receive community-based care or who are in a residential treatment facility and for their families.

CARES serves Illinois youths who are under 18 if they are not covered by private health insurance, are eligible for public funding, or if their private insurance coverage is exhausted or does not include mental health treatment. CARES and SASS also serve youths under 21 if they are enrolled in the All Kids health care program and/or if they have Medicaid coverage. Families with private health insurance coverage can get emergency help through community mental health providers.

Safety is critical. Before a crisis, you should alert police about your child's illness. This will increase the chances that in an emergency, police will understand that your child's actions could be caused by illness. Ask your local police to record this information in the police computer system along with your address, to alert emergency responders.

Call 911 if a situation is out of control and you fear that your child or someone else could get hurt. However, when police come you may lose control of what happens. Tell the police dispatcher that your child has a mental illness, and ask the dispatcher to send a social worker or police officer with Crisis Intervention Training (CIT). CIT officers have special training to handle mental health crises.

When police arrive, tell them if your child may become upset if someone touches him or her, yells, or stands too close. If police or social workers cannot calm your child, tell the police that you want your child to go to a hospital for evaluation and treatment, not to a police lock-up. Tell police if you have a preferred hospital. Before an emergency, it is wise to research which hospitals are in your insurance network and where your child's doctor has admitting privileges.



Funding for Residential Placement

Financial help may be available to pay for a residential placement for your child.

Funding sources include:

- **Individual Care Grant**
- **Local school districts**
- **Private health insurance**

Individual Care Grants

The Individual Care Grant (ICG) is a state-funded program that pays for residential treatment or community mental health services for youths with severe mental

illness, as documented by psychiatric evaluation, psychological testing, and medical and educational records.

ICG eligibility is based on severity of illness, not behavior, so some youths with dangerous behaviors do not qualify for this grant. Youths must be under 17½ years old at the time of application and enrolled in a school or other approved educational program. Youths can continue to receive ICG funding until they reach age 21 or graduate from high school, whichever comes first. The ICG is good for one year, and must be renewed annually. (See Appendix C, pg. 38 for ICG eligibility information)

You can get an ICG application by contacting the Illinois Mental Health Collaborative or the ICG coordinator at your community mental health center. The application requires information including social history, educational and medical records, and psychological testing and evaluations of your child. Testing and evaluations may be provided for free by your school district, or the cost may be covered by your health insurance.

You will be assigned an ICG coordinator who should be knowledgeable about grant criteria, the application, and available services. It is part of the ICG coordinator's job to help you complete the application. The application is extensive, and it is very wise to use this assistance. Tell your ICG coordinator what you will need to complete the application, or if you have questions about any other part of the process. If your ICG coordinator is too busy or is not accessible, you can call his or her supervisor or the Illinois Mental Health Collaborative.

The Mental Health Collaborative reviews applications to determine eligibility and administers the grants under supervision of the Illinois Dept. of Human Services, Division of Mental Health. If your application is denied, you can appeal and re-apply with additional information.

To get an ICG application,
call the Illinois Mental Health
Collaborative at:

1-866-359-7953 (voice)

1-866-880-4459 (TTY)

Learn more about ICGs at:
www.dhs.state.il.us/page.aspx?item=33654

ICG Program rules are in Title
59 of the Illinois Administrative
Code, at: www.ilga.gov/commission/jcar/admincode/059/05900135sections.html

When your child receives an ICG grant, you keep all your rights and responsibilities as parent or guardian, even if your child goes to a residential placement.

You choose how to use the ICG. You can use the grant for residential treatment or for community services, such as therapy or respite care, that may enable your child to remain at home. The ICG pays for therapeutic treatment and room and board at a residential school or for support services in the community. The ICG also may pay for activities, such as a park district class or a YMCA membership, that can help your child to build social skills or boost his or her overall well-being. In the past, grants also have funded support services such as special recreation programs, art therapy, and music therapy.

Your ICG coordinator will help to assess your child's needs and develop an individual service plan. Based on this plan, the ICG coordinator can arrange community services, or help you select an appropriate residential placement. If you choose a residential placement and your child has an IEP, your local school district pays tuition costs. You are responsible for your child's ordinary expenses, including transportation and clothing costs, spending money, and medical and dental care.

A goal of the ICG grant is to keep parents and family involved in the child's life, and to maintain and improve family relationships. Parents are required to participate in their child's treatment and education and discharge planning. Some ICG children return to their home and local school district when they are discharged from a residential program, and others go on to a group home, an independent apartment, a vocational training program, or to college.

Parent support

When your child receives an ICG grant, you will be invited to join a support group called the Illinois ICG Parents Group. The ICG Parents Group offers invaluable support and information through meetings and expert speakers, held approximately every other month.

In addition, the ICG Parents Group offers a Yahoo message group that can link you to other parents online. This online community communicates through email messages and exchanges information, resources, and support. You will also find many files containing valuable information on the Illinois ICG Parents Group Yahoo site. (See Appendix B, pg. 36)

If your child does not have an IEP

Most often, a student with an ICG or other funding for residential treatment also has an IEP, and the school district where the parents reside is responsible for funding and overseeing the child's educational services.

However, if the student does not have an IEP, the home school district does not have this responsibility. If your child does not have an IEP, you can initiate the IEP process by contacting your school district special education department to request a Case Study Evaluation. This will determine if your child qualifies for an IEP, and if mental health issues are affecting his or her educational progress.

If a student has an IEP and residential treatment is paid privately or by any entity other than a school district or the ICG program, parents can request that the school district fund special education services through the IEP process.

Funding for Residential Placement cont'd.

If you want to seek school district funding for residential placement, you should contact your school district's special education department and request an Individualized Education Plan (IEP) meeting to discuss your child's needs.

More information can be found in an ISBE publication called *Educational Rights and Responsibilities: Understanding Special Education in Illinois* at http://isbe.net/spec-ed/html/parent_rights.html

To learn more about school district-funded residential placement, you can go to: http://www.isbe.net/spec-ed/html/nonpublic_se.html

The list of residential schools on the ISBE placement list is at: www.hbug.k12.il.us/pfs

You can also call the ISBE Office of Special Education at 217-782-5589

Local school districts

Local school districts must pay for placement in a residential treatment center (RTC) when a team that includes parents or guardians, school district representatives, and special education teachers determines that residential treatment is required for the educational progress of a student with special educational needs.

Federal law requires public school districts to provide special education services to meet the needs of each child in the **least restrictive setting appropriate for the child**. Residential placement is the most restrictive option, because the child no longer lives at home or attends his or her local school. For this reason, a plan for the appropriate discharge back to the community is required from the beginning of placement.

Typically, school districts require trials of less restrictive options, such as a special education program in the home school district or a day program at a therapeutic school. A record of attempts to meet your child's needs in less restrictive educational settings often is required before a residential placement will be recommended.

Placement decisions are based on each child's Individualized Education Plan (IEP). The IEP is a written plan that describes a child's unique needs and goals and the extra assistance the school district will provide to help the child reach these goals. Parents have a right to request that their child be evaluated for a disability and, if a disability is diagnosed, to help develop the IEP for their child.

When an IEP team determines that residential placement is necessary for educational reasons, the school district must pay the costs of this placement, including tuition and room and board. School districts pay these costs using federal funds administered by the Illinois State Board of Education (ISBE).

School districts must prepare an IEP for each student, age 3 through 21, who is eligible for special education services. The IEP is written

by the IEP team, which includes parents or guardians, special education teachers, school district representatives, and experts who are invited by the parents or the school district.

It is important to know that:

- **Only the IEP team has the legal authority to make placement decisions.** Parents are very important members of the IEP team, but other team members have equal decision-making authority.
- **Schools are required by federal and state laws to educate each child in the least restrictive environment.** In order for residential placement to be approved, it must be determined that a child cannot benefit from educational services without 24-hour care.
- **IEP teams can only place a child in a residential facility that is on the Illinois State Board of Education’s approved placement list.** (See box, above) A child or youth with an IEP cannot be denied services because a school district lacks a particular program or resources, according to a federal law called the Individuals with Disabilities Education Act (IDEA). If appropriate programs do not exist within a local district, the district must locate and provide those programs, regardless of the cost.

High school graduation

School districts have a responsibility to provide an appropriate education for each student until his or her high school graduation. However, not every student graduates after 4 years or the accumulation of a certain number of

academic credits. According to IDEA, students with an IEP can continue in publicly funded educational or vocational programs until their 22nd birthday.

Students with special needs can graduate “by IEP.” This means that achieving IEP goals can be the standard for graduation, in addition to the required academic credits. The IEP team may determine that a student is ready to graduate when he or she attains social, emotional, and transition IEP goals such as better managing emotions or learning to use public transportation.

Private insurance

Some health insurance policies cover residential placements for children and youths with mental illness. Coverage for residential treatment may require a referral from a physician. When your child is at a residential treatment center, the insurer will be billed for medical and dental services. Medications, psychiatric monitoring, and medication administration also may be billed. If you are unsure about your health insurance coverage, you should contact your insurance provider or your employer’s human resource department for assistance.

For information on insurance regulations, or to make a complaint against an insurer, contact the Illinois Department of Insurance at: <http://insurance.illinois.gov> or call 877-527-9431.

Other resources

The Community and Residential Services Authority

The Community and Residential Service Authority (CRSA) is a free resource for any parent who is trying to find community-based services or residential treatment for a child under age 22 with a severe mental illness or behavior disorder.

Funding for Residential Placement cont'd.

CRSA helps parents learn about available public and private funding for community or residential treatment. CRSA also helps parents get adoption subsidy for a publicly or privately adopted child. In addition, CRSA can coordinate services between a school district and multiple agencies to arrange the right care for a child.

CRSA also helps to resolve disputes between parents and school districts or state agencies when there is no clear statutory responsibility for which entity should pay for needed care. CRSA brings together school districts, agencies, and service providers to create a team recommendation. Although CRSA does not have legal authority to impose a solution, CRSA has been very successful in getting funding commitments for services recommended by the team. For more information, contact CRSA at:

100 N. First Street, W-101
Springfield, Illinois 62777
Toll Free: 877-541-2772

CRSA has legislative authority to:

- Reduce barriers to services
- Provide technical assistance to help parents and others get needed services
- Help communities develop or strengthen provider networks
- Plan for a more responsive and coordinated service system
- Resolve multiple agency disagreements about funding for needed services

Social Security Supplemental Income

Children and youths with mental illness may be eligible for Supplemental Security Income (SSI). SSI is a Social Security Administration program that pays monthly benefits to disabled children and adults with limited income and resources. To qualify for SSI, a child must have chronic “physical or mental conditions that very seriously limit his or her activities.”

If your child lives at home, family income and assets figure in determining SSI eligibility. If the child lives at an RTC or is over 18, family income and assets are not considered. For more information, go to www.ssa.gov or call the SSA toll-free at 800-772-1213. An SSA claims representative can help you apply, or you can apply online and/or with the help of a lawyer.

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 can learn more by contacting DCFS at 312-814-6800 or www.state.il.us/dcfs

To learn about possible subsidy for a child who was adopted privately, contact CRSA (see above). For additional post adoption services and supports, visit www.state.il.us/dcfs/post_adoption/ or download the “Post Adoption and Guardianship Services” booklet at www.state.il.us/DCFS/docs/CFS%201050-45%20Post%20A-G%20Services.pdf

Medicaid

Parents can apply for Medicaid health care assistance through the Illinois Department of Human Services (IDHS) office or by calling the IDHS Helpline at 1-800-843-6154. If your child has qualified for SSI, it is likely that your child will be approved for Medicaid. Medicaid covers medical expenses including doctor bills, hospitalization, and medications. If your child has Medicaid and you also have private insurance, you should inform service be billed first, and Medicaid will pay the remaining costs. As with Social Security, family income affects eligibility for a youth under age 18 who lives at home.

“I really struggled with the decision to put my daughter in a residential facility. I wondered, ‘What is going to happen to her? How is she going to be treated? How is she going to accept this?’ It’s so important to ask a lot of questions and to find the right facility for your child.”

—Christina



Residential Placement Options

Choosing a residential treatment center (RTC)

It is very difficult to entrust your child to the care of others. It is important for you to feel confident that the RTC director, therapists, psychiatrist, teachers, and staff will properly care for your child. The RTC staff should communicate regularly with you, and should respond promptly to your questions and concerns. You should have a feeling of trust in the program and those working with your child.

Selecting an RTC also requires matching your child's needs to the specialized programs and treatment style of the residential facility. Take your time and gather as much information as you can. Visit several placement options and speak with the parents of students at these residential facilities. Talk with your school district, your ICG coordinator, and other parents in the ICG Yahoo Group or in your community about their RTC experiences.

There are many factors to consider. Some RTCs serve youths with specific diagnoses or behaviors, and many offer help for students with co-occurring disabilities, such as learning disabilities. Some RTCs offer vocational programs or college-preparatory classes and are best suited to students on those tracks. Some operate on a psychiatric treatment model and others stress behavioral therapy within the school community.

Distance, travel, and environment are also factors to weigh when choosing an RTC. Some facilities are far

from home and you may be required to bear travel costs. Distance also may limit visits and your ability to see your child in an emergency. RTCs are located in a variety of urban, suburban, and rural areas, with dormitory-style housing or scattered cottages. Visiting rules also vary. Some RTCs encourage students to spend weekends and some school breaks at home and others expect most visits to occur on campus.

Placement options also depend on your funding source. If you receive school district funding, you must choose an RTC on the ISBE-approved list. If your child has an ICG, you must choose an RTC that is approved for ICG recipients. Your ICG coordinator can provide a list of approved RTCs. Generally, you will be limited to residential providers located in Illinois. In order to receive ICG funding for an out-of-state placement, your child's ICG coordinator must provide documentation that your child was not accepted by three in-state providers.

When you have narrowed your RTC choices, consider taking your child to visit with you. Your child will be frightened and anxious about the move to a residential facility. He or she will be living away from home, perhaps for the first time, among new peers, in an unfamiliar place. Seeing the facilities, meeting staff, and learning about classes and daily activities can ease your child's fears and help him or her know what to expect. Ask the RTC staff how they help new students make friends and adjust to a new environment.

Issues to Consider

Before you visit

What are your child's needs? Can these needs be met while your child is at home with the right community support? Your ICG coordinator can help you assess local services.

Is an admission interview with your child required? If so, which staff member(s) will meet with your child? What medical and educational records will the RTC need?

Ask for written information about RTC rules and procedures regarding home visits, phone calls, behavior management, crisis intervention, physical restraint, safety, participation in religious services and activities, meals, activities after school or on evenings or week ends, medical and therapeutic services, and the transition to home or community. You can also review the RTC's website for information.

Ask your ICG coordinator, the special education staff at your school district, and other parents about any problems or serious ongoing issues at any RTC you are considering.

During your visit

If you did not receive a written copy of the RTC policies and procedures before your visit, ask again. Make sure that the information matches what you see and hear.

Try to visit when residents are at the RTC and engaged in their typical daily routines. Observe interactions between the staff and the residents.

Ask to visit the building or unit where your child would most likely reside. Talk to a staff member who regularly works in that residence.

About the facility

Is the RTC accredited? By which accrediting agency? Ask about the accreditation requirements, and request a copy of the RTC's most recent accreditation review.

If your child has allergies or other medical issues, what precautions or accommodations will be made? How are medical emergencies or ongoing medical needs handled?

What can or should your child bring to the RTC, such as clothing and personal items? What is prohibited, such as over-the-counter medications, glass containers, etc.?

Is the facility clean and in good repair?

About treatment

What type of mental, emotional, and/or behavioral issues does the residential provider most frequently treat? Does the provider have the expertise to treat your child's needs?

How does the RTC measure success? What is their success rate?

Given your child's diagnosis and needs, how long is your child likely to remain in residential treatment? What is the typical length of treatment at this facility?

Issues to Consider cont'd.

What is the model of treatment? Why is that model used?

Will your child be treated by a psychiatrist, therapist, and/or a physician at the RTC? Or can your child continue to be treated by his or her current doctors and therapists?

How does the RTC administer and assess the effectiveness of psychiatric medications? How and when will you be contacted about changes in your child's medication?

What extremes of illness and behavior are the RTC able to manage? When would the decision be made to hospitalize and where would a child be hospitalized? Does the RTC psychiatrist have admitting privileges to treat your child during a hospitalization?

What therapy services are provided? How many hours each day or week will your child participate in individual, group, and family therapy?

What type of therapy may be used for your child, such as Cognitive Behavioral Therapy (CBT)? Are these evidence-based practices, meaning practices proven to be effective? Ask about any concerns that are specific to you and your child.

What are the training and credentials of the staff?

How will the RTC determine if treatment is working? How is treatment reviewed and adjusted? How will the RTC inform you about your child's treatment and progress?

How does the program ensure that residents feel safe in treatment?

Do staff members work with the same group of children or do they rotate? What is the turnover rate for therapists and other staff who work directly with the children?

How will you be informed of your child's progress? Will you be able to talk to your child's treatment team, or will you communicate through a case manager or other designated staff member?

When and how will you attend family therapy? How is family therapy conducted?

What social or recreational activities are offered after school, on evenings and weekends? Ask for a schedule.

Describe examples of difficult times at home and ask how the RTC would handle those types of situations. Be open about your child's challenges. It's important for you to know whether the RTC can handle any extreme needs or behaviors.

How will the program work with you to identify your child's strengths? How will the program use those strengths in treatment?

Will the program allow your child to start or continue in community activities or employment that supports those strengths or talents?

Will the program teach you strategies to help manage your child at home or in your community?

What life skills are taught and how? For example, will your child learn to do his or her laundry, budget money, or use public transportation?

Parent contact and home visits

Will you be allowed to make unannounced visits to your child?

How will the school and staff communicate with you? Is there one person you can contact for treatment, educational, financial, or administrative questions?

How are parents and families involved in RTC programming? Can you volunteer to help with your child or assist in other ways, such as at family events?

Is there a parent association or other opportunities for parents to meet, support, and mentor each other?

Behavior and crisis management

RTCs are required to develop a Behavior Management Plan that details how crisis and problems will be handled with every child. Ask how your child's plan would be individualized, and what behavior incentives and consequences might be used?

What training does the staff receive in behavior management, crisis intervention, medical emergencies, etc.?

Ask about physical restraint and seclusion policies, situations in which restraint or seclusion may be used, and how you would be informed if these practices were used with your child. (Typically, parents are notified within 24 hours.)

Ask for examples of how crises are handled. Crises might include fights or aggression among residents, physical injuries, runaways, and alcohol or drug use.

How does the program communicate with parents about any serious incident? How quickly will you be notified? Will you receive a written report?

If a resident runs away or is hospitalized can he or she return to the facility?

Education

Where would your child attend school? Does the RTC have its own school, or do residents attend area public or private schools? Will you and your child have a choice?

What are the academic expectations? Is the school able to provide the educational services that are prescribed by your child's IEP?

Is your local school district involved? (If your child has an IEP, the school district where parents reside is responsible for funding and oversight of educational services.)

Who at your local school district and/or the RTC is responsible for talking with you about your child's academic progress?

How do the residential staff and the school staff communicate, and how often? Do they have regular meetings to share information and coordinate their efforts?

Issues to Consider cont'd.

If your child returns to his or her home school, will your child have the required classes and credits to keep pace with peers?

Will your child be prepared to pursue his or her goals, such as employment or college?

Discharge and Transition

Where do the residents typically go when they are discharged? Do students return home, live independently, go to college, or move to another residential facility?

Is it possible for you to talk to former residents or the parents of former residents?

Does the residential provider have transition programs or links to adult services that can help your child make the transition?

What must the youth do to be prepared for discharge? What is done to prepare you for your child's discharge?

How are disagreements about readiness for discharge resolved?

What supports are available if your child wants to live independently after discharge?

How does the provider coordinate with your home school district to be sure all necessary supports are in place at discharge?

Youth involvement

How does the program work with youths to set goals when it is developmentally and medically appropriate?

Is there an advocate available to speak to youths when they have questions or concerns? How are disagreements or problems between a youth and a staff member handled? What is the grievance procedure if youths have a complaint?

Does the agency have a youth advisory body or student council?

Cultural concerns

How does the program understand and address cultural and religious differences? Does the RTC have experience working with youth from backgrounds similar to your child?

Does the staff receive training in diversity issues? Does the program have staff from diverse backgrounds?

Will your child be a minority in the program? If so, how will the program address that?

After your visit

Review the written materials you have collected. Did what you saw and heard match the written policies and descriptions?

Were you comfortable with the staff? Do you feel you can trust the staff?

Were you comfortable with the other residents?

Do you agree or accept the program's philosophy, policies, and procedures? If not, keep looking. If you have more questions, call and ask or return for another visit.

*“You don’t give up your rights when your child goes to residential.
You don’t lose your child—this is still your child.”*

—Chrisa



Parents Rights and Responsibilities

When your child goes to an RTC, you remain important in every aspect of your child's life. As long as you are legal guardian, you retain the all rights and responsibilities of that role.

If your child is 17 years old or under, he or she is a child according to Illinois law, and you have the right to participate in education decisions and to be informed about, and approve, medical and mental health treatment. However, if your child reaches 18 while at an RTC, your child may have to give permission for you to receive some information.

In most cases, when your child is 17 or under, you have a right to:

- Be informed about and approve any medical or mental health treatment, except in emergencies.
- Be contacted to approve medication changes.
- Be notified as quickly as possible about any crisis or serious incident involving your child.
- Review all records pertaining to your child.
- Participate in IEP meetings and goal setting
- Participate in transition and discharge planning

When your child turns 18 years old, he or she is legally an adult. This means that your child has the right to make many decisions for him or herself, including the right to demand discharge from a residential facility against treatment advice.

Parents can gain some legal authority by going to court to ask a judge for guardianship of a disabled adult child. If you are guardian, you will have certain rights, such as the ability to make some decisions about education, residential placement, and medical care. As guardian, you can

admit your child to an RTC or a hospital, but you cannot force your child to stay. Guardianship requires proof that an individual is completely unable to make decisions about his or her personal life and/or finances. You may want to discuss the benefits and limitations of guardianship with an attorney familiar with this area of law.

More information can be found in:

Educational Rights and Responsibilities: Understanding Special Education in Illinois, at: http://isbe.net/speced/html/parent_rights.html

The Delegation of Rights to Make Educational Decisions can be downloaded at: http://www.isbe.net/speced/pdfs/nc_deleg_34-57k.pdf

Your ability to make educational choices for your child can continue seamlessly without guardianship if your child signs a Delegation of Rights to Make Educational Decisions form. This allows a student over age 18 to name a parent or other individual to make educational decisions, be present in IEP meetings, and to be informed about educational matters.

“So much depends on parents’ level of involvement. It is very important to be in touch with the RTC staff. They have a lot of kids, and they may not call you.”

—Kay



Residential treatment works best when parents and providers are partners

When your child goes to an RTC, you no longer see him or her daily, but you remain central in your child's life. No one can replace you as parent. Family support is fundamental for a child to succeed in a residential program, and to make a successful transition back to home, community, and into adulthood.

It is also essential to have frequent contact with RTC staff. You are your child's best advocate and it is important to share your unique knowledge about your child, to monitor your child's treatment progress, and to voice any concerns you may have. Don't worry about bothering the RTC staff; your questions and concerns are important. If the treating psychiatrist, therapist, or teachers are not accessible, you can call a supervisor, right up to the RTC director.

Some funding sources, such as the ICG, require parental involvement as a condition of funding and renewal. It is wise to maintain records of your participation. List the dates of phone calls and meetings with your child and RTC staff members, family therapy, and visits with your child at the RTC and at home. You may be asked to report on these activities annually, and your notes will help you to document your ongoing involvement.

While your child is at an RTC, you will be responsible for the costs that parents or guardians normally pay for their child. These include:

- Medical and dental costs
- Clothing
- An allowance or spending money
- Transportation costs for the child to and from the RTC.

The RTC may be able to pay for some of these items if there is a demonstrated financial need. Check with your case manager or the RTC business office to find out if they provide need-based assistance. Subsidies may be available to help families to travel to participate in family therapy and to visit their child. Local school districts also may help to pay for a child's transportation.

Family therapy

You and your child should participate in regularly scheduled, ongoing family therapy while he or she is in residential placement. Most RTCs provide this therapy as part of their program. Family therapy sessions can help you and your child deal with the many issues created by the child's illness. A child in residential placement should grow emotionally, socially, and behaviorally. In order for this growth to be sustained, families need to grow and change with their child.

When family therapy begins varies depending on the child's needs and the RTC policy. Some facilities wait for a period of time to assess the child, while others expect immediate involvement. Tell the therapist if you or your child are not emotionally ready for therapy. You should have a clear understanding about the expectations and goals of therapy. Feel free to question the therapist or to request a private meeting, without your child. This can give you a chance to get acquainted with the therapist before you meet as a family.

Most RTCs encourage family therapy once or twice a month, depending on parents' availability and the child's progress in treatment. It is your responsibility to keep appointments or inform the therapist in advance if you

are unable to attend and why. If frequent travel to the facility is impractical, these sessions can be held over the phone or by video conference.

Residential team meetings and progress reviews

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

Treatment teams typically meet quarterly to formally evaluate each child's progress and to review the treatment plan. Parents are integral members of the treatment team. You should be notified of these meetings in advance, and should make every effort to attend in person or by telephone.

Psychiatric planning

You should meet or speak periodically with the psychiatrist treating your child at the RTC to discuss your child's progress and medications. You can also help the psychiatrist by preparing a medication history showing what medications your child has been on, the dosages and the reason each was stopped. The RTC psychiatrist should be accessible to address any questions or concerns you may have.

Clinical appeals

If you disagree with the treatment your child is receiving, you should first discuss this with the case manager or clinical director at your child's RTC. There also may be a process for clinical appeals set by your child's school district or funding agency. Parents also have the right to seek a different RTC placement. Contact your funder for more information.

Parent support

Parents often feel very isolated when their child has severe mental health challenges and is in residential treatment. It helps to talk to others who understand. RTCs often offer some form of parental support beyond family therapy. This can be in the form of a parent association or a formal support group.

Some facilities also offer parent training, and expert speakers or activities that bring parents together. You are encouraged to participate in all forms of parent support. You can gain a great deal from the experience, and also help others navigate through this difficult period. If no support group exists at your child's RTC, parents can propose one to the RTC program director. Parent support programs should not be prohibited or discouraged by the RTC. There are also outside parent support options, including online groups. (See Appendix B, pg. 36, and Appendix C, pg. 38, for more information on parent support groups and self-care)



Contact with your child

Visit, call, email, send cards, and write to your child as often as possible. Your child may fear being rejected or forgotten while he or she is away at an RTC. Your child needs you to remain actively involved in his or her life, education, and treatment. It can be healing to look for ways to have fun with your child, especially when there has been conflict. Your child needs to know he or she is loved, no matter what painful events may have occurred.

Visiting your child at the RTC

Every residential treatment facility has its own visiting policies. Ask for a written copy of the visiting rules before you go. Some RTCs provide housing for family members for overnight or weekend visits. Some do not allow visits during a settling-in period of a week or even a month. Visits also may be determined by your child's progress in therapy (the child may "earn" longer visits) and/or the needs of the child and the family, including safety concerns. Most RTCs encourage frequent family contact, as long as this doesn't have a negative effect on the child's progress in treatment.

Ask how visitation decisions are made at your child's RTC, and ask to be included in these decisions. Be wary of programs that have arbitrary visitation rules, such as not allowing any visits, or cancelling visits without a clear reason. You should also let the RTC staff know if you have concerns about visiting, especially if your child is not doing well in treatment, or if you feel that a visit might be unsafe or could undermine treatment.

Visits allow you to spend time together as a family. They are also a great way to see how your child is progress-

ing and to support and motivate your child. Work with your child's treatment team to establish goals for each visit, no matter how small, and report back to the team how your child and family did. **Keep your own log of visits and notes about your child.** This will assist you in measuring treatment progress, and will also document your involvement in your child's treatment.

Telephone calls

Each facility has its own procedures for phone calls between children and their families. Calls may be scheduled at a certain time and day each week, or may occur at different times depending on schedules, how long the child has been at the RTC, and how well he or she is doing in treatment. Often, calls are discouraged for the first week after a child arrives at an RTC, to allow the child time to adjust. Calls may be monitored so that a staff can offer therapeutic guidance or intervene if necessary. The RTC must obtain your consent for monitoring.

The importance of consistent phone calls between you and your child cannot be underestimated. Messages of hope and caring are conveyed from parent to child through consistent phone calls. Schedule these calls during a time when there are few distractions.

Home visits

Home visits can allow your child to practice coping skills outside of the supportive environment of the RTC. Visits also can nurture family bonds and smooth your child's transition back home after discharge. However, visits can be stressful, and they require preparation and safeguards.

*“When I first considered bringing my daughter home for a visit,
I was really anxious. I thought, ‘I don’t know how this will go.’”*

—Christina



Contact with your child cont'd.

Your child's progress in treatment and ability to function safely at home and in your community are important factors in determining when and for how long a visit should occur. Your family's readiness is also important.

Let the RTC staff know if you have concerns about visits, especially if you think that a visit may be unsafe. Make a plan with the RTC staff so that you know what to do if your child has a crisis or refuses to return to the RTC. You always have the right to say no to a home visit, to limit the length of the visit, or to return the child to the RTC earlier than planned.

Safety is always the first priority. If there is a crisis and you fear someone could get hurt, call 911.

Ask about the RTC's home visits policies, including frequency and restrictions. In the beginning of your child's residential placement, home visits may be more limited. Distance, and school and work schedules can also play role in arranging visits.

Often, children feel anxious as the time to leave home and return to the RTC approaches. You may be able to lessen this anxiety by letting your child know that his or her cooperation will make future visits easier. An RTC staff member also may be able to reassure your child by phone or, if necessary, the RTC may send a car and staff to ensure safe transport. If at any time you do not feel it is safe to bring your child home, or you think your child will forcibly resist returning to school, you can tell the RTC and your child that he or she is not ready to visit.

There are many things to consider before bringing your child home for a visit.

For example:

- Is your child safe outside of the residential facility? Will your family be safe while your child is at home for a visit?
- What is your crisis plan?
- Will a home visit undermine treatment progress?
- How can you return your child to the RTC early if needed?

Your child will require close supervision and clear rules at home. Ask about RTC rules and how privileges are earned; you may want to reinforce these practices at home. Ask if your child should see hometown friends, go on family outings, or have certain restrictions at home. RTCs often discourage residents from seeing fellow residents on visits outside of the facility.

Home visits can provide valuable information to the treatment team about your child's ability to function outside of a very structured environment and his or her readiness to be discharged. RTCs generally ask parents to report verbally or in writing about home visits. It's important to be open about what went well and what did not go well, so that the therapeutic staff can help your child and family anticipate problems and have successful visits.

The Treatment Plan

Every child in a residential placement has an Individual Treatment Plan. As the parent, you are ultimately responsible for your child's treatment, and you have an important role in treatment planning. This planning begins as soon as the youth enters the RTC, and sometimes even before.

Accreditation agencies typically require RTCs to provide these assessments:

| Assessment | Time frame | Staff responsible | Update |
|---|--------------------------|---------------------------|-----------------------|
| Admission Note and Initial Assessment | 24 hours after admission | Case Manager or Clinician | Reevaluated quarterly |
| Mental Health/Rehabilitative Assessment | Within 14 days | Multidisciplinary staff | Yearly |
| Individualized Treatment Plan | Within 30 days | Clinician assigned | Monthly or quarterly |

Admission Note and Initial Assessment

The Admission Note and Initial Assessment give the staffing team guidelines to begin treatment. Parents or guardians provide information for both documents, and usually will receive a copy of the Initial Assessment. Both should be available to you upon request.

Mental Health Assessment

The Mental Health Assessment must be conducted soon after your child arrives at an RTC. This assessment tells about your child's needs and sets initial treatment goals. It could be quite lengthy and might involve input from several staff members. Your input is very important. You should be involved in developing this assessment, and you should receive a copy upon request. The RTC is expected to conduct an interview with you and your child in your primary language.

Individualized Treatment Plan (ITP)

All RTCs must prepare a comprehensive treatment plan for each child. This written plan may be called by different names, but for the purposes of this guide it is called

the Individualized Treatment Plan (ITP). Parents should receive a copy of the ITP. It is important to know what your child's goals are, as well as how you can help your child achieve these goals.

The ITP should include:

- Your child's diagnosis or diagnoses
- Your child's strengths and assets
- Goals, methods, and expected outcomes of treatment
- Evaluation of your child's progress toward treatment goals
- A list of needed services and the staff responsible for them
- Your child's estimated length of stay in the program
- A discharge plan
- Where your child is expected to live after discharge
- A signature page, signed by you, your child, and members of the treatment team

Setting goals

The ITP should include clear goals and objectives for your child. If the language in these documents is confusing or includes unfamiliar terms, ask the therapist or other staff to explain. You have a right to understand everything that is in the ITP. Discuss the plan with your child, and make sure your child understands what is expected of him or her in treatment.

The Mental Health Assessment will determine many of the initial treatment goals. Later, goals will be determined by your child's behavior and progress. Some goals will be general, under broad categories such as medical care and case management. These categories are necessary to ensure accurate Medicaid or insurance billing. Other goals should address the reasons your child is in need of

The Treatment Plan cont'd.

residential treatment, such as anger management, aggression, peer interactions, and family issues.

Goals should be age-appropriate and include an array of emotional, educational, and life skills. These achievements will be different for a 13 year-old than a 17 year-old. Because family participation is an essential part of the success of youth in treatment, family involvement and family therapy also should be a part of the ITP.

Treatment Plan review

Your child's ITP should be reviewed at least every three months, in a meeting called a staffing. Some programs review ITP progress on a monthly basis. Parents have a very important voice in staffings, and should provide input on their child's functioning and progress. These meetings also provide an opportunity for parents to ask questions and have input on treatment goals.

A staffing should include therapists, teachers, and, if possible, the treating psychiatrist. Psychiatrists usually are only at the RTC for a set number of hours, and are not always able to attend staffings. Your child's therapists should have regular contact with the psychiatrist, and should be able to report on your child's psychiatric treatment at the staffing.

Case management

The case manager should coordinate all aspects of treatment to ensure that everyone works together in the best interest of your child. Case management involves arranging services, advocating for the child and family, overseeing the treatment plan, reviewing the child's progress, and communicating with the family. The case manager should be accessible to you, and should also take an active role in all key meetings concerning your

child, including weekly treatment team meetings, monthly or quarterly ITP meetings, and IEP meetings.

The facility may refer to the case manager by other titles, including case coordinator or clinical coordinator. It is important to know who has this responsibility for your child.

Transition planning

Transition planning lays the groundwork for living independently as an adult. Schools are required to provide transition planning for all IEP students beginning at age 14 ½. The plan should evolve with the youth throughout his or her placement, and should list post-placement goals in education, employment, and living arrangements, and how the youth might meet those goals.

The transition plan should be age-appropriate and take into account your child's unique strengths, preferences, interests, and needs. The plan may include return to home and a traditional school with community supports. If your child is high school-age or older, the plan also could include preparation for college entrance exams, vocational training, and coaching on independent living skills, such as managing money or using public transportation.

When a child is at an RTC, this planning involves the home school district, the RTC staff, parents, and other providers who will assist the child in reaching his or her goals. You can give the school a list of the agencies and other providers that you want to be included in this planning.

Information on specific transition documentation requirements for schools can be found in *Educational Rights and Responsibilities: Understanding Special Education in Illinois*, an ISBE publication at: http://isbe.net/spec-ed/html/parent_rights.html

“The first word that comes to mind when I think of discharge is ‘scary’. There’s so much to do and, ultimately, the parent is the one who has to make sure everything is in place.”

—Debra



Discharge planning

The time to begin thinking about your child’s discharge from an RTC is at admission. How long a child remains in a residential placement should be determined by each child’s needs and progress in treatment.

When your child goes to an RTC, your child and family adjust to this change over a period of months. Discharge planning is the process of returning the child home or to another placement or living arrangement, and this change requires gradual adjustment as well.

Discharge plans should include:

- Continuing mental health care and community support services
- Educational planning
- Vocational planning
- Activities and recreation
- Assessment of risk factors and a crisis plan

Discharge planning cont'd.

Residential treatment centers are required to begin assessing and planning for discharge as soon as the child arrives. This planning becomes much more detailed and specific in the final months before discharge. Most youths return to their home and community after RTC treatment.

It might be most helpful to think of the initial discharge plan as the “ideal goal” that the treatment team is working to accomplish. Discuss with your child’s case manager the skills your child needs and how he or she must behave and function in order to leave the RTC and remain safe in your home and community.

Early in this process, you should ask how the RTC prepares residents for discharge. Some facilities offer teens and young adults opportunities for greater independence while maintaining supervision. These may include the chance to live in a supported apartment, to take a class at a nearby college or arts center, to volunteer, or to hold a part-time job outside of the RTC. These experiences can help youths learn independent living skills and gain confidence, while still receiving support and supervision.

It is understandable to feel anxious or worried about your child’s discharge. It helps to view this process as a plan that is written and reviewed over time to meet the changing needs of your child and family. As a member of the treatment team, you have an important voice in discharge planning. Other members of the treatment team, including school district officials or other funder, and RTC educational and therapeutic staff, also share decision-making authority.

If you disagree with the treatment team’s discharge decision, you can ask your school district or funder for information on procedures to contest or appeal the decision. You also may want to consult with an attorney who is familiar with special education law.

Parents should play a large role in the discharge plan. Make sure the treatment team knows about your concerns and family limitations as well as strengths and supports that might aid in your child’s transition. You can also ask your child what worries him or her about the transition and return home, and what supports or services might help.

When your child is about six months from expected discharge, you should begin to identify community-based providers and other services near your home. Be vigilant about determining what services are available in your community, because all services are not available in every community. Ask your ICG coordinator or special education director for assistance in locating services.

Your child should not be discharged from the facility without a very detailed discharge plan that specifies where, when, and who will provide services. This plan should include appointments with therapists and other providers, and should be ready to be implemented as soon as your child leaves the RTC. The discharge plan should outline supports and services extending at least six months after discharge. (See Appendix D, pg. 39, for a discharge planning timeline)

Maintaining your child's well-being

Aftercare

After discharge from an RTC, youths with mental illness almost always have a continued need for mental health care. It is important to make appointments for your child and prepare services, so that there will not be a gap in treatment or medication. Without follow-up care, there is a significant risk that your child will regress or lose the gains made while in placement. Aftercare may be paid for through private health insurance, public funding such as Medicaid, or through your child's RTC funding source.

Ask your school district, funding source, or ICG coordinator to help you identify and arrange services for your child in the community. Your child is likely to need psychiatric services, individual therapy, and community support services including recreational activities. You and your child also may benefit from continuing family therapy. Be sure that your child is discharged with enough medications to last at least a week, and prescriptions that can be filled after that.

There may be setbacks. Ask your child's RTC if you should contact the RTC in case of a crisis soon after discharge, or if you should seek help from a community mental health agency. Contact your child's community mental health provider before discharge and make sure they are familiar with your child's diagnosis, needs, and challenges and are prepared to help.

Educational and vocational services

Education is an essential service to all children. In addition to providing learning opportunities, it allows for

socializing and structure in 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 and classroom needs may have changed. Parents and the RTC educators and therapeutic staff must collaborate with the homeschool well in advance of discharge to assess your child's educational and vocational needs and put detailed plans and educational resources in place. There should not be a lapse in education services when the child returns home.

Community supports and recreation

One of the things parents report as being most helpful in their child's transition back home from residential placement is a well structured daily schedule. Children in residential placement have had daily schedules 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.

As part of transition and discharge planning, you, your child, and the treatment team should discuss your child's social and recreational interests. You can also contact your local park district, special recreation district, and school district to find out about available activities. Before your child leaves the RTC, make sure activities are in place. These activities can help your child meet peers who share similar interests. These relationships can be important for your child as he or she works toward continued health and well-being.

Adult mental health services

All youths transition to adult services at age 18. When a youth with ICG funding reaches age 17, a formal period of transition should begin, with continued financial assistance and guidance to access services. ICG planning for adult services can take a year, and should begin well before grant eligibility ends. (See Appendix F, pg. 41 for a transition planning timeline)

The switch to adult services begins when an ICG Transition Manager sends information about the youth to the adult mental health network that serves the youth's home community. The ICG coordinator should help the youth and family plan services, which can include mental health care, vocational training, and assistance with living arrangements.

Funding is currently unavailable for ICG transition assistance, which in the past has provided financial assistance in the first year after discharge from the ICG program. It is wise to apply early if you plan to seek assistance for expenses including public trans-

portation, community college tuition, apartment rent and other assistance for your child after discharge.

Transition plans should be in place at the time your child graduates from high school or turns 21, whichever comes first. If your child needs services to help him or her live independently, it is especially important to begin this process early because these services require extensive planning.

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 should expect more involvement from the residential provider and the ICG coordinator. If your child is using ICG services in the community, your ICG coordinator should be involved.

If your child does not have ICG funding, your community mental health providers can link your child to adult services. If your child has Medicaid, this public funding also may open doors to additional services and community supports.

Conclusion

The goal of community and residential treatment is to build resilience and improve lives. Treatment can help struggling youths learn to manage their illness, succeed in school and employment, improve relationships, and live fulfilling lives. Resilience helps an individual to rebound from adversity and move forward with a sense of hope and competence. This can be a very challenging process, but with the right knowledge, care, and support, you, your child, and the whole family can benefit from placing your child in a residential treatment center.

Appendices

- A. Checklist for residential placement
- B. Parent support groups
- C. Parent self-care
- D. Eligibility criteria for the Individual Care Grant
- E. Discharge planning timeline
- F. Transition to adulthood planning timeline
- G. References and resources
 - 1. Acronyms
 - 2. Values and Principles for the System of Care
 - 3. Family Driven Care Guiding Principles

Appendix A: Checklist for residential placement

1. Is residential placement right for your child and family? Compare available community-based services and residential placement options.
2. Explore funding options. Ask your school district to assess your child's needs, apply for an Individual Care Grant (ICG), or seek coverage through your private health insurance.
3. Get a list of approved residential treatment facilities from your funding source.
4. Get recommendations for facilities that might meet your child's needs. You can ask the special education staff at your child's school, your ICG coordinator, your health insurer, or other parents.
5. Visit potential placements, ask a lot of questions and gather information.
6. After you choose a residential facility, meet with the staff member who will be your main contact. Build a relationship with this person, and keep in close touch.
7. Join a parent support group. You can benefit from the support, experiences and shared resources of other parents who understand.
8. When you and your child are ready, take part in family therapy.
9. Continue to be active in your child's life through visits, calls and letters.
10. Take an active role in planning your child's education, treatment, transition and eventual discharge. What are your child's hopes and goals, and what supports and services will your child need to succeed?

Appendix B: Parents support groups

Illinois ICG Parents Group

Parents of youths with ICG grants are invited to join this group. The ICG Parents Group offers support and information through meetings and expert speakers. In addition, the ICG Parents Group offers a Yahoo message group that can link you to other parents online. This online community communicates through email messages, and exchanges information, resources and support. You will also find many files containing valuable information on the Illinois ICG Parents Group Yahoo site. Parents of youths with ICG grants will be invited to join this group.

The Balanced Mind Foundation

Online support and information for parents of youths with mood disorders
www.thebalancedmind.org

National Alliance on Mental Illness (NAMI) of Illinois
www.illinois.nami.org

NAMI of Greater Chicago Chicago

Family support groups
Meets 2nd Wednesday of each month from 7-9 p.m.
1536 W. Chicago Ave., 1st floor
Chicago, IL 60642
312-563-0445

NAMI Cook County North Suburban

Basics Support Group for parents of children and adolescents

Kenilworth

Meets 2nd Thursday of each month from 7:30-9 p.m.
at Kenilworth Union Church
211 Kenilworth Ave.
Kenilworth, IL

Wilmette

Meets 3rd Friday of each month from 9:30-11 a.m.
at Wilmette Public Library
1242 Wilmette Ave.
Wilmette, IL

NAMI of DuPage County

Wheaton

Meets 2nd Monday and 4th Tuesday of each month at 7 p.m.
NAMI DuPage County Office
2100 Manchester Road
Building B, Suite 925
Wheaton, IL 60187
630-752-0066

NAMI of Lake County

Mundelein

Meets last Thursday of every month at 7 p.m.
Gracepoint Church
1221 Maple Ave.
Mundelein, IL
847-249-1515

NAMI of Northern Illinois

Rockford

Support Group for Parents of children and adolescents
Meets every other Thursday 6:30 p.m. Offers free child care
Mildred Berry Center
8616 Northern Ave.
Rockford, IL
815-985-6495

Family Support

Meets 3rd Tuesday of every month at 7 p.m.
Our Saviors Lutheran Church
3300 Rural Rd.
Rockford, IL
815-985-6495

NAMI Livingston/McLean Counties

Bloomington

Basics Support group for parents of children under 18
Meets 3rd Saturday of every month from 1-3 p.m.
St. John's Lutheran Church
Everson and Towanda Streets
Bloomington IL
309-212-0581

Other parent support groups:

Arlington Heights

Meets 1st & 3rd Friday of the month at 6:30 p.m.
Northwest Community Hospital
Behavioral Health Building, 2nd Floor Education Room
901 W. Kirchoff Rd.
Arlington Heights, IL 60005

Oak Park and River Forest

Fred Parent Support Group
Meets monthly at the
River Forest Public Library
735 Lathrop Ave.,
River Forest, IL 60305
jeandmeister@aol.com

Naperville

Support group for parents of children,
adolescents and young adults
Meets Mondays, 6:30-8:30 pm at:
Linden Oaks Hospital
852 West Street
Naperville, IL 60540
630-305-5500

Champaign

Meets 2nd Tuesday of the month from 6-8 p.m. at:
Champaign Public Library
200 W. Green St.
Champaign, IL

Peoria

Meets 3rd Wednesday of the month from 5:30-7:30 p.m.
At Center for Prevention of Abuse
1225 N. North St.
Peoria, IL 61606

Rock Island

Meets 4th Wednesday of the month
Martin Luther King Jr. Community Center
1529 Third Ave.
Rock Island, IL 61201

Springfield

Meets 4th Tuesday of the month from 6-8 p.m.
Lincoln Prairie Behavioral Health Center
5230 S. Sixth St.,
Springfield, IL 62703
217-585-1180

Jacksonville

Meets 1st Tuesday of the month 6-8 p.m.
Passavant Hospital
1600 West Walnut St.
Jacksonville, IL 62650
217-245-9541

Petersburg

Menard County REST Parent Support Group
Meets 3rd Wednesday of the month, 6-8 p.m.
Petersburg Community Center
18 George St.
Petersburg, IL

**To locate post-adoption
family support groups, visit
www.state.il.us/dcfs/post_adoption/**

Appendix C: Parent self-care

Caring for a child with a mental illness can take a lot of time, energy, and patience. It is important, for all members of the family, to take time to care for themselves and focus on their own mental and physical well-being.

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.

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 around you—and learn to accept it in 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 during the day.
9. Find support groups both on the Internet and in the community.
10. Above all else—learn to laugh and to play.

Keep in mind that we are better caregivers when our own needs and wellness are tended to.

References: *Individual Care Grant Parent Handbook* and “How to Heal Yourself: The Curing Power of Hope, Joy, and inner Peace.” From *Peace, Love and Healing* by Siegel, Harper, and Row, 1989.



Appendix D: Eligibility criteria for the Individual Care Grant

The Individual Care Grant (ICG) program is governed by Illinois Administrative Code Title 59 Part 135. The criteria below must be met in order for a grant to be awarded. The ICG funds the cost of intensive community-based care of residential treatment.

1. Parent/guardian must be a resident of Illinois. (135.30 (a))
2. The child must have a severe mental illness. A severe mental illness is defined as a mental or emotional disorder, which substantially impairs thought, perception of reality, emotional process, judgment, behavior or ability to cope with the ordinary demands of several life domains. Symptoms must include severely impaired reality testing and may include hallucinations, delusions, avoidance or withdrawal from human contact, marked affective instability, apathy, bizarre behavior, deficient or unusual forms of communication, agitation and/or danger to self or others. The course of the illness should indicate that the symptoms do not represent acute episodes from which rapid and substantial remission is likely. (135.30 (b))
3. The child must be enrolled in an approved educational program.
4. The child is not past the age of 17 years and six months before submission of the completed application. (135.20 (f))



Appendix E: Discharge planning timeline

| 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 community-based options for aftercare planning |
| 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/ICG Coordinator/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/ICG Coordinator | Final D/C Date is determined |
| 2-4 weeks prior to D/C | ICG Coordinator/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 | ICG Coordinator/ RTC/Parents | Complete plan is in place. Education plan, mental health care, recreational activities, & respite begin |
| Immediately after D/C | ICG Coordinator/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. |

Appendix F: Transition to adulthood planning timeline

| Time Frame | Activity | Responsible Party | Final Result |
|--|--|---|---|
| Child reaches age 14 | IEP includes transition to adult services as a goal, begins to plan for needed resources | Local school district or RTC. Parent may need to remind local school district to begin transition planning. | Assessment and plan for adult education and vocational needs, updated at each IEP meeting |
| Child reaches age 16 | Discussions of adult needs become more detailed and focused | Family, mental health providers, recreation providers and other community supports | Ongoing dialog bringing all parties together to develop plan |
| Child reaches age 17 | ICG* information is sent to the adult mental health network | ICG program | Adult mental health network becomes aware of child's status and pending transition to adult services |
| Child reaches age 17** | Ongoing planning involving the young adult, family, RTC, school district, mental health providers (SASS or RTC), | Parent or guardian should ensure that the rights services are in place. Parents should expect significant assistance from RTC, SASS, the adult network and the local school district. | Needed resources are identified and available. |
| 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 him or her into adulthood |
| Child graduates from high school or reaches age 21, whichever occurs first | ICG funding ends. The young adult remains eligible for 1 year of transition funding to be used for community based support | ICG transition manager, ICG coordinator and SASS worker, adult network and family. | Young adult has support and is linked to adult education or vocation, recreation, mental health and independent living services, as needed. |

*Additional detailed information regarding ICG transitions, is available through the ICG Parent Yahoo Group.

**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.

Appendix G1: References and resources

Diagnostic acronyms

ADD – Attention Deficit Disorder
ADHD – Attention Deficit with
Hyperactivity Disorder
ASD – Autism Spectrum Disorder
BD – Behavior Disordered
BP – Bipolar Disorder
BPD – Borderline personality disorder
or bipolar disorder
BP-NOS – Bipolar not otherwise
specified
CD – Conduct Disorder
COD – Co-occurring disorders
EBD – Emotionally and Behaviorally
Disturbed
ED – Emotionally Disturbed
or Eating disorder
FAS – Fetal alcohol syndrome
GAD – Generalized Anxiety Disorder
LD – Learning Disabled
MDD – Major Depressive Disorder
OCD – Obsessive Compulsive Disorder
ODD – Oppositional Defiant Disorder
PDD – Pervasive Developmental
Disabilities
PTSD – Post Traumatic Stress Disorder
RAD – Reactive Attachment Disorder
SAD – Seasonal Affective Disorder or
Separation Anxiety Disorder
SID – Sensory Integration Dysfunction
SMI – Severe Mental Illness

Other acronyms

ADA – Americans with Disabilities Act
BMP – Behavior Management Plan
CBT – Cognitive Behavior Therapy
DBT – Dialectical Behavior Therapy
DCFS – Illinois Department of Children
and Family Services
DD – Developmental Disorder
or Developmental Delay
DHS – Illinois Department
of Human Services
DSM – Diagnostic and Statistical Manual
of Mental Disorders
DX – Diagnosis
ECT – Electro-Convulsive Therapy
ESY – Extended School Year
FAPE – Free Appropriate Public Education
FAB – Functional Behavior Assessment
FERPA – Family Education Rights
and Privacy Act
HX – History
ICG – Individual Care Grant
IDEA – Individuals with Disabilities
Education Act
IEP – Individualized Education Program
ISBE – Illinois State Board of Education
ITP – Individualized Treatment Plan
LCPC – Licensed Clinical Professional
Counselor
LCSW – Licensed Clinical Social Worker
LEA – Local Education Agency
LSW – Licensed Social Worker
LTC – Long-term care
NAMI – National Alliance
on Mental Illness
ORS – Office of Rehabilitation Services
(part of DHS)
OT – Occupational Therapy
Pdoc – Psychiatrist
PRN – Prescribed for use as needed
R/O – Rule out
RTC – Residential Treatment Center
RX – Prescription
SA – Substance abuse
SASS – Screening, Assessment,
Support Services
SPED – Special education
SSRI – Selective serotonin
reuptake inhibitor
SSI – Supplemental Security Income
STEP – Secondary Transition
Employment Program
Tdoc – Therapist or psychologist
TX – treatment
UIR – Unusual Incident Reporting Forms

Appendix G2: Values and Principles for the System of Care¹

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) 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

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

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

Appendix G3: Family Driven Care Guiding Principles²

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.

“It’s the repetition of affirmations that leads to belief. And once that belief becomes a deep conviction, things begin to happen.”

—Muhammad Ali



Rebounding from adversity and moving forward with hope and competence can be challenging, but with the knowledge, care and support of residential treatment, you and your child and your entire family can build better relationships and achieve success in school, work and life.



For more information, contact

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