

#### Family Tip Sheet (Expanded Version)

### **Tip Sheet for Families Considering a Residential Program**

Information for Families and Caregivers

**USING THIS FAMILY TIP SHEET:** Family members of children who have received residential services helped prepare this Family Tip Sheet so that you and others can benefit from their experience. Please use this Family Tip Sheet to help you (1) think about what is most important to you and to your child and (2) decide which questions you might want to ask when considering a residential program for your child.

f you are considering a residential treatment program for your child—or if your child has just been admitted to a residential program—you probably have many questions. This Family Tip Sheet is designed to help you get the best care and treatment for your child with emotional and behavioral challenges.

Residential programs are designed to assess and stabilize children so that families can be reunited as quickly as possible, given the needs of the child and family. The best programs work with and for families and children: they collaborate and help families discover what works to help their child flourish.

Practically speaking, there may be limits to how much choice you have about where your child receives services. If you feel strongly, though, that the plan for your child is not in his/her best interest, you should be assertive about asking for alternatives and find someone you trust who is willing to work with you to develop a safe and appropriate plan. In most cases, even if you do not have custody of your child, you still can and should be involved in making important decisions about his or her treatment.

Remember that you have the right to have a voice in the decision-making about where your child receives treatment. Don't be afraid to ask questions or challenge policies that don't make sense or don't seem right to you. Work closely with providers to help your child. Many providers will be very open to your ideas and understand that you know your child best. If you run into serious roadblocks along the way, seek out a family partner, a supportive provider, or another advocate to help you.

deally, the answers to all of the following questions should be "yes"—but some compromises and choices may be necessary. Many excellent programs will not meet all of these criteria, but the more families and programs work together, the closer programs will get to doing so. If a program, however, is not family-friendly or the answer to any of the questions about safety or whether the treatment is right for your child is "no," then you may want to consider other options. No one should accept unsafe, inappropriate or disrespectful treatment.

You can be a valuable and active member of the team of people who work with your child while he or she is in out-of-home care. Through teamwork, you can build a bright future for your child.

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### **Building Bridges Initiative**

#### 1. HOME OR AWAY?

Is a residential program really the best place for my child to receive treatment right now? Are there services in the community that would work?

Being away from home is hard for everyone -- especially children--and no institution is as healing as a loving family. Although residential treatment programs can appear to be safer than home, this is only true if your child genuinely needs a restrictive setting, the program is well-run, and the staff has been properly screened and trained.

As a result, residential programs are best used sparingly to achieve a specific goal like respite, assessment, medication stabilization, or learning particular skills in preparation for return to the community.

If you are considering a residential program, keep in mind that many community-based resources are not wellpublicized. There may be more intensive services in your community that might be able to help you and your child without the need for residential care. If you think that additional or different services could help you provide support for your child at home ask an advocate in your community or your provider to help you explore those options.

Other questions to think about:

- Why are you seeking placement for your child?
- Can these needs be met while your child is still at home if you get a different kind of help? (For example, some children need more support in school and some families need respite that can be achieved in other ways.)
- Have you explored all the available community-based resources thoroughly, including programs that may be affiliated with nearby academic centers and universities?

### 2. RIGHT PLACE NOT JUST ANY PLACE

# Does this particular program have the best available expertise for children with my child's specific needs and challenges?

Just because your child is eligible for a program—or because a slot is open there—doesn't mean that that program is right for your child. It's important to discover whether the program can demonstrate that it has the specific expertise needed to help your unique child and successful experience with children with similar challenges.

If possible, your child should get the most thorough assessment available from the best expert you can find in the condition your child has (for example, a psychiatrist who studies autism, a psychologist who has published

research on ADHD). That assessment can help guide your decision. This expert should not be affiliated with a particular residential program.

Ideally, the residential program should be located as close to home as possible to make visiting easier. This is true regardless of the reason for placement.

Other questions to think about:

- What type of emotional and behavioral concerns does the residential program treat most often?
- Does the program have expertise with the type of needs my child has?
- What is involved in the treatment and why is each particular technique used?
- What are the different therapies that will be used?
- What goals will my child need to meet in order to be discharged?
- How will my child be able to function differently after treatment?
- How long do staff think it will take for my child to be ready to return home?

#### 3. SAFE PROGRAM

## Is the program licensed and accredited? Have all staff had criminal background checks and have they been cleared through the state's child abuse registry?

There are no federal regulations for residential treatment programs for children with emotional and behavioral problems. State regulation varies widely and some programs advertise that they can help such children even though they are not licensed to do so. Some states send children out-of-state to residential programs that are not appropriately licensed in the state in which they are located.

Consequently, it's important to check licensing and regulation information thoroughly. Programs should be licensed by the state where they are located to provide each of the specific services they are offering to your family. They are accredited either by JCAHO, COA or CARF (but note that this does not guarantee that a program is safe or appropriate for your child). All staff have passed criminal background and child abuse registry checks and have appropriate training for their positions.

To learn about possible problems with any program, search online for news accounts relating to the facility and contact the Better Business Bureau and the state attorney general's office to learn if there have been any serious, ongoing issues.

Other questions to think about:

- Which state agency licenses the residential program?
- What state agency licenses the educational services at the program?
- Is the program accredited? By which agency?
- What training is provided to the staff members who work day-to-day with the children?
- What kind of supervision does the staff have?
- Have all the employees been subject to background checks? By which organization and what kind of screening has been done?

- Does the program take children's medical complaints seriously, with a "better safe than sorry" approach, not one that assumes children with behavioral challenges are "faking"?
- How does the program communicate with caregivers about any serious incidents?

### 4. EFFECTIVE SERVICES

# Are the techniques used by the program supported by research studies on children with similar needs?

While medications have to be proven safe and effective before they can be marketed, there is no government agency that approves or rejects talk therapies or behavioral treatments. As a result, we don't really know whether many of the approaches used in residential treatment work.

The best programs base their care on scientific evidence, ideally using techniques that have been shown by research to be safe and effective with particular types of children. Quality programs also tend to have the most highly educated staff, particularly amongst those working day-to-day with the children.

Claims about "success rates" that aren't backed by research published in medical journals should be viewed skeptically. Quality programs have processes in place to learn what works and what doesn't work, overall, and for each child and they have adopted approaches that others have found effective.

Other questions to think about:

- What kind of research supports the techniques you are using?
- What did that research show about success rates?
- Has this approach been tested on the condition my child has?
- How will you know if the program is working for my child?
- How will you communicate with me about the outcomes of my child's treatment?
- How are programs reviewed and adjusted to work better?

### 5. FAMILIES ARE EQUAL PARTNERS

# Does the program make me feel like my opinion and ideas are important? Does the program involve me in decisions about my child during care?

You know your child better than anyone else does. Consequently, the best programs involve family members and other caregivers in as many ways as possible. Family members' perspectives are sought out and valued. Family members are on the agency's advisory board and have influence on the overall direction of the organization.

Phone calls and letters are encouraged, not monitored nor used to reward or punish children. Visits are encouraged and not limited to specific times. In fact, some of the most progressive programs are doing away with the concept of 'visiting'. These programs creatively involve family members in many aspects of the program and have an open door policy unless the child and family team has determined that there are compelling reasons to limit contact.

When a child is not doing well, family contact is increased, if desired-- and families are not treated as the problem, but as part of the solution. A family advocate or parent partner at the program can help make this partnership work.

Other questions to think about:

- How does the program involve family members in treatment?
- Does the program have an "open door" visiting and phone contact policy?
- What suggestions can the program offer to help me aide my child's recovery?
- Will the program teach me the strategies I need to help my child at home?
- Can the program provide the names of other family members I can talk to about their experience?
- Is there a family advocate or parent partner and how will they work with my family?
- Can funding be arranged for transportation or other expenses to aid visitation if necessary?

### 6. YOUTH HAVE A VOICE

#### Does the program empower a youth to guide his/her own recovery?

Being sent to a residential program can be a frightening experience even in the best of circumstances. Research shows that increasing the sense of control children have over their own treatment improves the odds of success. The more control people feel they have, the safer they feel-- and the safer they feel, the easier it is for them to learn.

Consequently, children should be given meaningful choices and allowed to set goals for themselves. To make sure that youth voices are heard, many high quality programs have a "child advocate" who can help with conflicts. The best programs actively involve children and youth in their own recovery.

Other questions to think about:

- What does the program do to help children set goals and guide their own recovery?
- Is there an advocate children can speak with when they have questions or concerns?
- Is there a youth advisory group that advises the agency and does it meet often?
- Can my child visit the program in advance to learn what to expect?

### 7. COMMUNICATION COUNTS

### Does the program communicate well with me and have a clear plan to consult me about important questions and decisions?

The best residential programs collaborate closely with your family and communicate clearly and openly about how your child is doing. This is crucial to treatment success. It shouldn't be difficult to contact staff and they should be in touch with you regularly. Staff should consult with you regarding how you have dealt with specific behaviors or disciplinary issues at home.

Communication is the key to avoiding problems like use of the wrong medications or disciplinary practices that have previously backfired.

Many good programs link new families with family members of children who are already in the program to help them navigate the system and get the most out of it. Programs may have family members or youth who have been through the program on their staff to be a resource to new families. This can help you communicate and feel empowered. With good communication, everyone involved is able to discuss even difficult issues which might arise during treatment. Don't be afraid to raise concerns or ask questions—this can help both you and your child and is not "trouble-making."

Other questions to think about:

- How will the program communicate with me? How often?
- Who specifically do I speak with to discuss issues or raise questions?
- How do you help families mentor each other?

#### 8. STRENGTHS MATTER

### Does the program consider the strengths of our family and help us discover and build on our strengths and those of our child?

When a family is faced with a child's emotional and behavioral challenges, it's often hard for them to recognize their own strengths. High quality residential programs help families locate and build on these strengths—in both the families and the children. They use the areas in which a child and family does well to build confidence and self-esteem.

Other questions to think about:

- How will the program help us identify our strengths?
- How will the program use my child's strengths to motivate him or her?
- Does the program have a way to help my child stay involved in or start community activities that allow him or her to develop hobbies and talents or pursue special interests?

#### 9. POSITIVE POWER

#### Does the program build children up, not break them down?

Some people believe that children with behavioral problems need "tough love." But research shows that the best therapies and types of care focus on building kids up, not breaking them down. High quality programs focus on children's positive qualities, not on getting them to accept stigmatizing labels. They do not force kids to "open up" when they are not ready to do so.

Research shows that empathetic and caring relationships between children and their therapists and other staff are most likely to be helpful and that confrontational or humiliating approaches are harmful.

Other questions to think about:

- How does the program view confrontation?
- What does the program do when a child does not feel safe sharing personal information?
- How are conflicts between children and staff handled?
- Is there a child advocate to mediate conflicts?

### **10. DISCIPLINE, SECLUSION AND RESTRAINT**

# Are restraints used only when a child truly endangers him/herself or others? Is the staff trained to reduce the need for restraints, apply restraints safely, and avoid the use of seclusion?

Unsafe use of restraint is one of the biggest risks children face in residential programs. Restraint and seclusion have no therapeutic purpose and can severely harm children if used inappropriately or for lengthy periods of time. Consequently, seclusion should never be used and restraint should only be used when a child is an immediate danger to himself or others. Face-down restraints are the most dangerous.

Quality programs do not use any kind of corporal punishment. They don't use disciplinary measures that reduce access to education or communication with parents and they never use restraint or seclusion as punishment.

Restraint is avoided as much as possible and there is a debriefing for the child and the staff after every use of restraint to see if another technique could have defused the situation and to try to prevent recurrence.

Other questions to think about:

- What are the program's policies on seclusion and restraint?
- How often is restraint used? Is the program engaged in a process to reduce the use of restraint and seclusion? Has the use of these procedures been reduced?
- What kind of training is provided to staff members who apply restraints?
- Is face-down restraint ever used?

### 11. CHILD AND FAMILY TEAM

Will all of the people working with my child meet or speak regularly with me (and my child if he or she is old enough) as a team to talk about my child's plan and how things are working?

A Child and Family Team (CFT) is the group of providers, educators, family members and others who know your child and who are working with your family to aid recovery. (Note: In some states, these teams have a different name.) You help select the participants and are included and encouraged to participate actively. Everyone on this team collaborates to ensure that all necessary services are received in a coordinated way at the appropriate time. If you do not already have a CFT, you should talk with your care coordinator to see if you can get some help to create one.

Until recently, residential programs were isolated from the outside world and disconnected from therapists or other providers that work with a family before and after placement. Now, we know that integrating all the services a family receives into a "system of care" is much more effective. The CFT helps make this happen.

Other questions to think about:

- Do you work with Child and Family Teams?
- If we don't already have one, can you help me start one?
- How will the residential program work with our Child and Family Team (if we already have one)?
- Which staff member(s) will attend CFT meetings or conference calls?
- How will the CFT guide my child's treatment?
- What role do family members and youth play on these teams?

### **12. EDUCATION**

#### Does the program offer my child appropriate educational opportunities while he/she is in care? What steps will be taken to be sure my child has a smooth transition back to a school in the community afterwards?

Education is crucial to life success and this is especially true for children with emotional or behavioral challenges. While some programs provide education on-site, others use local schools or other providers to meet the educational needs of participants.

High quality residential programs ensure that children have access to the best educational resources including certified teachers. If the child's current teachers and/or school representatives are on the Child and Family Team it is more likely that there will be effective communication. Is there a plan in place to be sure that your child doesn't fall behind and that all of his/her credits transfer when he/she goes home.

Other questions to think about:

- How does the program provide education?
- Are the teachers certified?
- If education is not provided on-site, how do you coordinate with teachers and other educators to ensure school success?
- Who will be on the CFT with regard to my child's education while in residential care?
- How do you coordinate with our school district to be sure my child has needed school support services in place when he/she is discharged?
- Will my child return to his/her school on track to complete the year with the right number of credits

### 13. CULTURE AND LANGUAGE

Are the staff members interested in and respectful of my culture? Will staff communicate with me and with my child in our own language?

Although it is obvious that a child who doesn't speak English won't benefit from a program that literally does not "speak his language," there are many other cultural issues that are not so immediately visible. These can have a huge impact on how your child fares in a residential program.

The best programs are "culturally competent"-- that is, they recognize that different cultures have different approaches to child-rearing, different norms for family roles, and different understandings of mental health. These programs work with families to ensure that cultural differences are recognized and valued, not dismissed or misunderstood.

Other questions to think about:

- How does your program work to understand cultural differences and address them?
- How much experience do you have working with children from our background?
- What training has your staff had in addressing these issues?
- Does the program hire staff members from different cultures?
- Will my child be a "minority" in the program, and if so, how do you address that?

### 14. CONNECTED TO HOME AND COMMUNITY

Is the program going to support us when our child comes home? Does the program keep children involved in community activities even when they are in care? Does the program prepare adolescents to live independently?

Among the most difficult times for children and families are the transitions into and out of residential care. The best providers ensure that your child and your family have the educational, vocational, family, and community supports needed during and after discharge. These connections produce the best outcomes.

As much as possible, high quality programs involve children in the community and use approaches that carry over into life back home. They teach families how to use these techniques to maintain their gains. All children should be learning skills that will help them be successful in the community.

In contrast, some programs use "point and level" systems (where a child has to earn a certain number of points to progress to a higher level of privileges and can be set back for failures). These do not prepare children to cope outside of residential care and there is no evidence that these systems aid recovery.

For children who are leaving residential care as young adults, quality programs ensure that they have a place to go that will support them and that there is appropriate aftercare, education, and job training or placement arranged in advance.

Other questions to think about:

- How will you prepare my child for transitions?
- What techniques will you use with my child that I can use at home to help?
- How will we be sure my child has the life skills he/she needs to function in the world?
- What can be done to support my adolescent who wants to live on his/her own after discharge?

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### 15. TRAUMA ISSUES

## Does the program understand that many children have experienced overwhelming stress and/or trauma? Does the program work to avoid situations that can re-traumatize children?

Many children with behavioral or developmental needs serious enough to require residential treatment have experienced some form of trauma and/or overwhelming stress. This can include losing a parent, being placed in foster care, suffering neglect, physical or sexual abuse or witnessing violence or serious accidents. For some children, ordinary experiences that would not be traumatic for others can be perceived and reacted to as traumatic.

Trauma is an experience of overwhelming fear and powerlessness and those who have suffered trauma are often exquisitely sensitive to situations that they feel they cannot control. High quality residential programs recognize this and do everything possible to make children feel safe and in control. Confrontational therapies, approaches that push children to discuss traumatic experiences if they aren't ready to do so or that try to elicit extreme emotions can re-traumatize these children.

Other questions to think about:

- How does the program deal with trauma issues?
- What does the program do to ensure that children who have experienced trauma feel safe in therapy?
- What other trauma-informed practices does the program use?

#### 16. MEDICATION

Does the program work with the child's doctors and others to learn the medication history prior to admission? Is the program using medications safely and appropriately?

Many children with emotional and behavioral challenges need medication. Often, residential treatment is used to find the best medications and eliminate those which are unnecessary or that have problematic side effects.

High quality programs work with families and their doctors to obtain a thorough medication history by the time of admission so that medications which have previously been tried and failed are not used again in the same way. These programs also notify parents of any medication changes or issues.

Programs vary in their philosophies on the use of medication. Research finds that some children are overmedicated and some are under-medicated—so the best programs don't take extreme positions favoring or opposing medication but work to find the best solution for each child. Prescribing practices are based on the best available current research. Medication is distributed by nurses or other medical staff—not by children.

Other questions to think about:

- Has the program consulted our doctor or otherwise obtained a complete medication history for my child?
- What is the program's philosophy on medication?
- How is medication distributed to the children?
- How will I be notified of changes or problems with medication?

### **17. ARE WE THERE YET?**

Does the program track whether my child is making progress towards his goals and make changes when needed? Can the program clearly describe what the criteria are for discharge? What will happen if there is a disagreement about my child's readiness for discharge?

In collaboration with families, quality programs track children's progress and set clear goals. Programs should be able to show through assessments and specific, measureable outcomes how your child is doing in language that you can understand. You should be able to monitor this progress and discuss what can be learned from setbacks. Don't be afraid to speak up if you feel that something isn't clear or that progress isn't being made.

Other questions to consider:

- How can I be sure that my child is making progress?
- What is your idea of what my child needs to accomplish to be ready for discharge?
- What can you do to help prepare our family for my child's homecoming?
- What happens when we don't agree about whether my child is ready for discharge?

As you can see, there are many, elements that go into sustaining high quality residential care. Consequently, even the best programs won't be the best in every single area—and that doesn't mean your child won't benefit. Again, the most important elements are safety and a nurturing, humane environment; if these are present, and the program is willing to work with you on the issues that you feel are important, that is a great place to start. Focus on the aspects of the program that matter the most to you and your child.

Having a child in a residential program can be difficult—but with knowledge about quality care, your family can make the best decisions and maximize your child's strengths, abilities and capacities.

## To locate an advocate in your area who can help you learn how to find the most effective services for your child, please contact:

The National Federation of Families for Children's Mental Health at <u>http://www.ffcmh.org/</u> 1-240-403-1901

This Family Tip Sheet is a product of the Building Bridges Initiative, a national effort supporting strong partnerships between residential and community providers, policy makers, advocates, families and youth towards implementing practices that are family-driven, youth-guided, strength-based, culturally and linguistically competent, individualized, evidence and practice-informed, and consistent with the research on sustained positive outcomes.

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