

POINTS FOR PARENTS

Considering Residential Care

March 2023

This document is designed to help families make informed decisions about care for their child or adolescent. It is not intended to promote or diminish the importance of any particular intervention.

The contents reflect the insight of parents who have faced decisions about residential care, research, and best practices.

Some items in the checklist at the end of this document have been adapted from the Magellan whitepaper, *Perspectives on Residential and Community-Based Treatment for Youth & Families*; Building Bridges Joint Resolution (Substance Abuse and Mental Health Services Administration); and A START (Alliance for the Safe, Therapeutic and Appropriate Use of Residential Treatment – USF).

If you are thinking about out-of-home care for your child or adolescent, your family is under a lot of stress. Your child's symptoms may have created difficulty at home or in the family; produced failure, trouble or suspension at school, or; led to problems in the community such as involvement with the police or child welfare. Your child may have been hospitalized without having received any other services, or may be taking medication that has not been effective. Your child may not yet have had a full psychosocial assessment to explain why they are experiencing challenges.

Many times, friends and family members do not understand behavioral health challenges or know how to support you and your child. If your child has siblings, they may also be responding to a world that feels out of control. They may feel isolated, anxious, overlooked or unimportant. Your personal relationships may be affected as you try to meet the daily demands that come with parenting a child or young adult with mental health needs or cross system challenges. *These situations create pressure for everyone to rapidly seek answers.*

Your child's school, pediatrician, or other providers may also be overburdened. They too can feel pressed to quickly find solutions. A sense of urgency can lead you to overlook options - or to settle for choices that may not fit the needs of your child or family. Though this crisis may compel you to make rapid decisions, we encourage you to pause for a moment and consider the information in this document before making a choice about where your child receives services.

Points for Parents Considering Residential Care



1. Connect with Other Parents for Information & Support

Your experience is unique, *but you are not alone!* Other children, youth and families have been in similar situations. While their solutions may not be the answer for your child, they can help you explore all of the possible resources. They can also share information with you about what has happened to them, and help you think creatively about what might work for your child and family.

Contact family-run organizations in your state that

advocate for children and youth with behavioral health needs and their families. If you are not certain about how to contact them, reach out to FREDLA (<u>info@fredla.org</u>). Other parents and caregivers can offer important information and support that no one else can. Parent peer support providers will help you find resources, stay engaged and help you and your child achieve positive outcomes.

2. Is Respite Available to You and/or Your Child?

Respite services are intended to assist children and youth to live in their homes and communities by offering temporary relief and skill building for the primary caregivers or youth. Respite services provide safe and supportive environments on a short-term basis for children with mental health conditions when your family or child needs a break.

Respite services are provided either in the home or in approved out-of-home settings. Both you and your child are experiencing stress. If your child has a plan of care, respite should be identified as a service need. Respite should build on the strengths, interests and skills of the youth/family while offering a change of pace until your child receives the necessary care and your family is feeling steady and supported.





3. Explore Community-Based Options

Residential services should not be the first option presented to you. If you have not yet received services in the community, share your concerns with your child's pediatrician or primary care doctor. They can refer your child for an assessment to determine why they are experiencing challenges. Your family run organization can provide navigation throughout this confusing time, help you connect with various service providers, and guide you to resources available to you and your child.

4. Learn About Services and Supports

Your child's behavior is the result of certain needs. Think about what type of service or support is required to meet those needs. *Try to think of needs and services* as you plan for your child and family. What does your child need in order to successfully live at home, achieve in school and be part of the community? Explore with your child's providers what supports or interventions already exist that could meet those needs. Could available services be reshaped for your child? Learn what types of support you can receive at no cost to you. If you do not readily see a solution, can one be developed with your family?

5. Natural Supports

Some of the things your child needs may be available through ways other than formal services. Informal and natural supports can help with social skills, emotional growth and feeling accepted as part of a family and community. Natural Supports are the relationships that occur in our everyday lives. Natural supports usually involve friends, co-workers, neighbors, roommates, and acquaintances who provide companionship, encouragement, camaraderie and a feeling of

security. Natural supports are the enduring supports in a family's environment; examples include people who celebrate with the family in good times, comfort them through difficult times, contribute to a sense of belonging, and may provide tangible assistance. Natural supports can help youth be engaged in community activities, volunteer, take on new challenges, gain a sense of accomplishment, or spend 'downtime' doing things that interest them. As you help develop a plan of care, explore the natural supports your friends, family and community can offer.



6. Find Your Own Services or Supports

The pain and grief associated with raising your child without resources can be overwhelming. You may feel guilt and question your own decisions. This is especially true if your child is separated from the family. You will be angry, disappointed, or resentful about systems and services that didn't work. Taking care of yourself now will better prepare you to support your child and family to get through - whether or not you select residential care.

7. Carefully Consider Residential Care when it Is Recommendedⁱ

When you have tried all practical services without success, you may want to explore residential care for your child or teen. Once again, you may feel pressed to make quick decisions. This sense of urgency increases when well-intended helpers say things like, "*if a bed is available*," or "*the facility has saved a bed for your child*," or "*there is a waiting list for these beds*." Finding the care your child needs is not as simple as being about beds – care should meet your child's needs and advance the goals of treatment.

Residential services should be considered a short-term intervention. Research shows that youth make their most significant gains within the first six months. Treatment should focus on helping your child and family achieve specific outcomes (not program levels or rules) and discover the root cause of your child's problem. Discharge planning should be based on the treatment goals that you and your child set at Deciding that your child be in a residential treatment program is difficult. When making a decision about a residential treatment program, it is important to consider the following information about your child:

- Evaluation data
- Current symptoms and behaviors of concern
- Previous treatments and interventions

• Reasons why other lessrestrictive program options such as intensive outpatient therapy, intensive inhome therapy, day treatment, or hospitalization are being ruled out.

(https://www.pacer.org/parent/php /PHP-c85a.pdf)

intake. Your child's progress toward those outcomes should be routinely assessed and inform whether treatment is effective or if new approaches are necessary.

Choosing a service and being comfortable with your choice is not an easy task. Involve your child in making the choice – the decision will affect your child more than anyone else – and will last a lifetime.

We encourage you to resist choosing a program or facility until you know more about it. What will this mean for your child and family? Making an informed choice requires you to get answers to several important questions. The checklist on the following pages provides some areas for you to consider.

NAME OF PROGRAM

MY CHECKLIST

OVERALL RATING 🔺 🖈 🖈 🖈

RATE THE PROGRAM YOU ARE CONSIDERING IN THE FOLLOWING AREAS

LOCATION

Being far from home can create complications for you and your child. It can cause added financial drain, emotional strain, and get in the way of family connections (siblings, parents, grands, etc.).

- Is the facility close to home?
- Will I have to limit visits because they will create a hardship?
- Does the program reflect or resemblemy community?
- Are there supports Included to keep and strengthen the bonds of my wholefamily? (including siblings)

SAFETY

- Does the program avoid exposing my child to extreme environmental conditions, overlytough physical activity, or trauma?
- Does the program provide a safe and clean environment?
- How is my child protected from other childrenor adults?
- How does staff respond to fighting, bullying and other aggressive acts?

ENVIRONMENT

- Was my visit welcomed?
- Could I visit all areas of the facility?
- Were staff comfortable with measking questions?
- Were all of my questions answered?
- Does staff reflect our family culture?
- Are all areas of the facility clean, including bedding and pillows?
- Is the atmosphere positive?

INDIVIDUALIZED APPROACH

- Can the staff give me a detailed explanation of the therapies, interventions and supports that will address my child's specific needs?
- Are they trained in traumainformed approaches?
- Will my child be able to enjoy their talents (music, sports, hobbies, art, writing, etc.)?
- Does the program focus on my child's own strengths and goals instead of achieving program levels or goals for discharge?
- Will staff respect my family's culture and rituals?
- How often will staff review my child's progress and adapt their approaches?

EDUCATION

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- Will the facility recognize and implement my child's educational plan?
- How will the facility involve my child's local school or school staff with whom we have a positive relationship?

RIGHTS PROTECTION

- Will staff contact me immediately in case of illness, injury, emergency or changes in treatment or medication?
- Will my child be able to contact me at will?

- Will my child be taught by licensed/certified teachers who have degrees from accredited colleges?
- Will the credits my child earns be accepted by our state's Department of Education and transferred to our home school district?
- Will the ratio of teachers to students permit my child to get the necessary level of educational support?

VALUE & RESPECT

- Will staff request my consent to contact providers and teachers who have worked with my child?
- Will they ask what my child thinks about the program and welcome feedback?
- Will staff encourage me to participate in allareas of my child's care?
- Will they encourage me and my child to honestly discuss what is happening in the program when they are not present?
- Will they listen to me and my child when we ask for changes? (adjust or change medication, more time at home, etc.)

HEALTH CARE

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- Are full-time, licensed mental health professionals on staff?
- Does the program contract with outside agencies or individuals to provide mental health services? If so, are these services available when needed?
- Is a psychiatrist regularly and frequently available to prescribe, monitor and adjust my child's medication?
- Is a physician regularly and frequently available to monitor my child's health and medication?
- Are medications administered by trained, qualified staff?
- Is a nutritionist available for the program?
- Will my child have access to a dentist on site? If not, is there a dentist readily available who understands children with complex needs?

- Are visits, mail and phone contact limited? Can I schedule a call with my child with little notice?
- Can I communicate freely with my child (no one listens in on phone calls or reads their messages or mail)?
- Does the program provide contact information to youth and families who feel their rights are being violated?
- How will the dignity of youth be preserved? (are tactics of shaming and humiliation prohibited, etc.)

SKILLS

- Does the program offer a chance for my child & family to develop skills that can be used at home, in the community and in life?
 - Problem-solving, anger management, etc.
 - Decision-making (do they teachbehavioral skills – or rely on discipline?)
 - Social skills
 - Independent living skills
 - Self-regulation
 - Effective communication
 - Other
- Can the skills and hobbies be continued at home without financial burden?

DISCHARGE

- Will the existing goals for my child and family be incorporated into the out-of-home plan?
- Will my child's pediatrician be informed of changes in my child's health or consulted when necessary?
- Will my child and family be part of planning for my child to come home?
- How will the school be prepared for transition?
- How will my family be prepared for and supported during transition home?
- What kind of in-home support is provided when my child returns home?

We hope this information has been helpful in your journey to access appropriate services for your child. Contact us to connect with a family organization near you <u>info@fredla.org</u>



Supporting your capacity to help children, youth and families!

Website: www.fredla.org