

A Guide to Exploring Out-of-Home Placement



INTRODUCTION

A Roadmap

No matter what the circumstances, the prospect of placing a child in a living situation outside the home can be daunting. As with most important decisions, exploring the range of possibilities is helpful. This guide is designed to help you navigate the options and prepare for conversations with other family members, the child's advocates, medical providers and others.

Points of Consideration

Here are some typical circumstances that prompt families to think about out-of-home placement:

- **Known Disease Progression**

Some parents are aware early on that their child will need more skilled care than they will be able to provide at home. Sometimes this is apparent at birth, or sometimes a disease has a foreseeable progression that leads to increasing care needs. That progression, whether physical, medical or behavioral—or some combination of these—may become unmanageable in the home setting.

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- **Shift in Baseline**

Parents may, over time, grow into the idea that their child might benefit from extended time outside the home. Sometimes there is an unexpected shift or continued health decline that triggers the family to consider out-of-home placement. A child who is spending increasing amounts of time in the hospital, or who has additional complications from a treatment or disease progression, may require more intensive medical care than is manageable in the home, even with outside support.

- **Change in Family Circumstances**

Transitions within the family may affect the ability to effectively care for a special needs or medically complex child at home. The option of out-of-home placement may come up at times of change in the family's life cycle (e.g., parental separation or divorce, birth, death, empty nesting) or when there are other health considerations within the family. These circumstances may prompt questions about the need to look outside the home for care.

- **When There is a Long Life Expectancy**

Parents of special needs or chronically ill children are often faced with the worry of who will care for their child when they are aged or deceased. When the illness trajectory is relatively long and the child is expected to reach adulthood, it is natural for parents to have concerns about how their own health will affect the care of their medically complex child. Parents may also anticipate that they will not be able to keep up with the physical demands of caring for a fully-grown adolescent or adult child as they themselves are aging.

Options for Living Outside the Home

These are the most commonly found out-of-home care models. Depending on the child's needs and the nature of the illness, families may discover just the right setting in their own community. However, some may have to seek care in other locations. Your disease community, social worker and/or care provider will have specific suggestions and recommendations to explore.

- **Residential (Boarding) School**

Some specialized schools offer a residential program. This option allows the child with specific needs to get the services and care they may not be able to get in their local community—and, in fact, offers the child a sense of their own community. Like a traditional boarding school, children live on campus during the school year, with breaks for holidays and summer vacation. During these breaks, families may have their child back at home, or at a respite facility or with another care provider.

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The benefits of residential schools include:

- Constant social interaction, in and out of the classroom, from morning to evening
- Gaining an appropriate level of independence with encouragement from staff whose goal is to empower the child
- Proximity and access to support resources without need to travel
- Extracurricular activities
- Life skills building

● **Skilled Nursing Facility**

Children with more complex medical needs, such as those who may be vent-dependent or require constant nursing care, are often best cared for in a skilled nursing facility. Pediatric skilled nursing facilities have 24/7 nursing care to address medical needs, while also supporting the child's social, emotional and developmental needs.

The benefits of skilled nursing include:

- Availability of trained specialists to administer medications and perform procedures
- Social interaction
- Education and training (depending on the child's capabilities and needs)
- Consistent caregivers, supervised with clinical oversight
- Low patient to staff ratios
- Flexibility in programming

● **Group Home/Supportive Housing**

Medical and transitional group homes offer varying levels of skilled nursing care and supportive mentoring in a home-like, community environment. Group home staff work closely with family members to integrate life between the child's home and the group home if and when appropriate.

The benefits of supportive housing include:

- Consistent caregivers, supervised with clinical oversight
- Low patient to staff ratios
- Flexibility in programming

● **Short-term Respite Care**

Many state and local agencies will offer families of medically complex children some form of respite care. Respite may be provided in the form of a small financial grant to help a family pay for in-home care or an opportunity for a child to be housed at a respite facility for short periods of time. Many families utilize these opportunities in order to participate in a family event, attend to a medical procedure, or simply to take a few days to recharge.

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Financing Out-of-Home Care

In the United States, financial assistance for out-of-home care is provided through a combination of state and local (city or town) agencies, mostly through contracts with the federal government. Each has its own policies and processes. Your social worker can help you understand the requirements and prepare the documentation you will need. In addition to speaking with your hospital team, it can be very helpful to speak with an attorney, family advocate, or local Legal Aid person. Some serve as volunteers and/or provide their services on a sliding scale that is based on ability to pay.

● **Special Needs Trust**

A Special Needs Trust is a popular instrument for financing longer term out-of-home and other care. This type of trust allows the beneficiary to use assets held in trust for their benefit, without jeopardizing assistance from government agencies. An attorney or advocate can provide advice on how to structure a Trust.

Emotional Aspects

When a child has a serious illness or becomes seriously ill, and it becomes necessary for the family to begin exploring out-of-home placement, a wide range of strong emotions and feelings may arise. Anticipating these, and naming them as they arise, can be a helpful coping tool.

● **Sadness and Grief**

Placement of a child is, to be sure, a loss. No matter how appropriate and caring the new environment, the child is no longer living in the family home. The life that the family expected to have with their child is changing again. Along with missing the child, making this decision may also be an acknowledgement that the illness or condition is advancing beyond the family's ability to provide the needed care.

● **Disappointment and Guilt**

As the child's needs progress, the family may need to confront hopes, dreams and expectations that their child's life might somehow have been different. Disappointment at not being able to keep the child at home, and feelings of sorrow, inadequacy, self-judgement and guilt, may result.

● **Anxiety Over Losing Control**

The prospect of handing over responsibility for the child can be especially challenging. In general, professional caregivers understand that the family knows the child best—and they will respect that knowledge in planning the child's care.

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● Anger

Parents caring for medically complex children may experience a heightened sense of anger or frustration. Almost all have moments of “Why me?” and/or “Why my child?” Considering out-of-home placement can bring these feelings to the forefront. Acknowledging them can help the family move forward.

● Fear of External Judgement and Stigma

It’s a fact: Few of us truly understand what others experience until we face the very same situation. However rational, or even essential, the choice of out-of-home placement may be, the family will likely face questions from outside the nuclear unit. Painful as it is to deal with external judgement, the most important question is whether this is the right choice for your child and family. It is not about what other people think. “That is the basis upon which the decision should be made.

Interviewing a Residential

Choosing the right residential, or extended care, facility for a child can be difficult if you are unsure of what to evaluate. Here are some important questions to ask when interviewing/researching a particular facility. Some of these questions are appropriate for a phone screening, others would be part of an on-site visit.

● Screening

- How does your team approach patient care? Do you have a philosophy of treatment?
- What are the issues you are best suited to treat?
- Can you tell me a bit about what it’s like to be here, or to be a family whose child is here?
 - What is the average patient age?
 - Are patients separated by gender? For what activities? (e.g., sleeping, recreation, meals, groups)
 - How does the treatment team communicate with parents (e.g., phone, email, Skype, visits)?
 - What access do parents have to the attending physician?
 - Do you have a recommended visitation program?
- Based on your understanding of my child’s needs:
 - How would your program benefit my child?
 - Understanding that you haven’t yet met my child, what are your initial thoughts about a treatment plan?
 - Have you worked with similar cases? What were the outcome in these situations?
 - How do you handle on-site visits? Would my child be involved?

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● On-site and After

- Based on your evaluation of my child:
 - How would they fit in with other residents?
 - How will you determine length of stay?
 - Do you have any concerns about my child's participation in your program?
 - What would be a realistic successful outcome for my child?

The ARC of Greater Cleveland also has a helpful, very detailed list of questions to ask a potential provider:

<http://thearcogreatercleveland.org/PDF/QuestionsForProviders.pdf>



CONCLUSION

The First Step Toward the Best Possible Outcome

Investigating and, if appropriate, choosing out-of-home placement is a journey. For some parents, it is challenging; for others, it brings a sense of relief and peace. There is no right way to do it, and there are no answers that work for every child and every situation. Preparing yourself with an understanding of your goals for your child, and awareness of how you want to interact with the treatment team, is a good first step toward the best possible outcome for the family.