Long Term Solutions: What if we just can’t do this anymore?

Sometimes, a team gels beautifully and medical supports and positive interventions are effective in bringing an individual with autism the sense of security and the skills he needs to thrive in his home or community environment. However, sometimes factors such as limited resources, dual diagnoses, biological triggers or learning history can mean that a family needs more support than can be provided at home, and alternate solutions need to be considered.

This is not an easy decision to make, and often comes with considerable stress for everyone involved. It is important to remember that this decision is NOT giving up on your child. In many ways, it is recognizing that your child needs more than you can provide, and taking the steps necessary to allow him to grow and thrive in a place that is able to provide what he needs. This might mean a place with a 24-hour staff who can provide something that is not possible for a single individual, or a residential facility that supports his physical concerns as much as his behavioral needs. It is hard to be consistent and upbeat and follow a behavior plan when you are exhausted and deflated. It is difficult to be a family and support each person’s needs, wants and growth, when everyone is afraid. Many families who have experienced a family member with significant challenging behaviors have reported on a much-improved relationship with their child once he was placed in a residential program that met his needs.

“If I could give any advice to parents going through this, I would tell them that it’s not always an easy road, and a lot of times it can be scary. But you aren’t alone, it can get better. I would tell them to reach out for help, because you can’t walk this road alone. Each day is a new adventure, new challenges and new successes.”

— DM, a mother

Residential placement is a personal decision that should be made when a family is no longer able to care for the needs of their child at home. For individuals with challenging behaviors such as aggression or self-injury, this may occur earlier in life than the usual transitions that occur in adulthood. It is also important to note that a residential placement is not necessarily permanent. If your team is able to build supports and skills and address underlying concerns, it may be possible for your child to return home.

A case manager or service coordinator from your school or social services agency can help to search for an appropriate setting for your child. Often, parents want to find something close to home so that they can maintain a relationship and contact with the child and his providers.

For help, visit these resources:

- Autism Speaks Housing & Residential Supports Tool Kit
- Autism Speaks Catalog of Residential Services
- National Disability Rights Network
- Disability.gov Housing Resources
- Global & Regional Asperger Syndrome Partnership (GRASP) – list and map of GRASP support groups
Where can we learn more?

Family and Caregiver Training

This tool kit is a lot of information in writing, and that is not always the best way to learn. Families who need additional information and supports will benefit from specific training and supports.

- **Hands on Training:** Ideally, this is from a behavior analyst or other behavioral provider who is part of your child’s team at school or home who can individualize training to your child's needs. It is individually designed to the needs of your child, your family, and responsive to the findings of the functional behavior assessment. It would occur in your home or in the settings where you need the assistance and training. Insurance laws are increasingly providing coverage for autism services, including ABA and behavior supports. Ask your doctor or case manager for suggestions.

- **State or local ABA or autism conferences:** Many conferences, presentations and workshops will focus on autism and case studies related to the treatment of challenging behaviors, or skills that might help to replace those behaviors. Visit [ABA International](https://www aba-international.org) to learn more.

- **Training Classes in Behavioral Approaches:** Parenting classes are often held at autism support groups, local hospitals, YMCAs, social services agencies, and the [National Alliance on Mental Illness](https://www.nami.org). Only some will be autism specific. These classes may provide you with tips and skills, as well as access to people and resources you might not already know about who can provide or suggest more specific services. [Mental Health First Aid USA](https://www.mhfausa.org) may also be a helpful resource.

- **Watch SuperNanny episodes on TV or YouTube:** She employs good behavioral strategies with respect to setting boundaries and expectations, staying calm, rewarding desired behavior and incorporating fun. These principles apply in autism just as they do with typical children.

- **Take care of yourself:** Parenting is hard enough, let alone when the demands of a child with special needs and challenging behaviors are added into the mix. Find strategies to improve your sleep, your resilience and your ability to remain calm and nourished. Classes in yoga, mindfulness and other stress reducers might be helpful. Talk to your friends and family, and find some time for fun. Seek out local supports for respite from community agencies, your place of worship or friends and family. Spend time with your other children and your spouse. Ask for help. Breathe. Visit the [Autism Speaks Resource Guide](https://www.autismspeaks.org) to find respite care and support groups in your area.

“My friends were always reaching out to me to get lunch or a cup of coffee. Most of the time I felt too busy to step away from taking care of my son. Any time away from his needs felt like I wasn’t being a good parent. One day my friend happened to call just as I was running out to the grocery store – she convinced me to meet her for a cup of coffee beforehand. Once I met her and sat down to chat and relax for a few minutes, I realized how much I needed it. I now make time every week to see my friends, or have a little ‘me’ time. Ultimately I think I’m a better parent and person because of it.”

— AC, a mother
Resources:

211 Database Service
Available in much of the US, this service connects people with important community services, sponsored by United Way Worldwide (UWW) and the Alliance for Information and Referral Systems (AIRS).

ABA Training & Treatment - Behavior Frontiers
Asperger Syndrome and Difficult Moments: Practical Solutions for Tantrums, Rage and Meltdowns
by Brenda Smith Myles and Jack Southwick
Managing Threatening Confrontations DVD
from the Attainment Company

No More Meltdowns: Positive Strategies for Managing and Preventing Out-Of-Control Behavior
by Jed Baker Ph.D.

The Way to A: Empowering Children with Autism Spectrum and Other Neurological Disorders to Monitor and Replace Aggression and Tantrum Behavior
by Hunter Manasco

Provider Training

Many schools and service providers will have trained staff accustomed to handling challenging behaviors. Others will not. Service providers who need additional information on positive supports and crisis prevention and management can utilize the following resources for information and training:

- Positive Behavior Supports
- Kansas Institute for Positive Behavior Support
- The New England Center for Children “CALM” Curriculum
- Safe and Civil Schools
- Crisis Prevention Institute
- Quality Behavioral Solutions to Complex Behavior Problems
- Mental Health First Aid USA
Conclusion

Autism can bring a family many challenges, especially when a loved one with autism exhibits behaviors that are challenging, disruptive, or dangerous. These are often experiences that our siblings, parents and best friends do not quite understand, since they have not necessarily faced the same concerns. As a result, many families with loved ones with autism experience significantly high levels of stress, which can be disruptive and unsettling. However, many families have also shown resilience and an ability to bounce back from the challenges that autism presents with humor, grace and increasing strength.

It is important to get help. Cry when you need to. Lean on your friends, extended family, and other social supports. Connect with other parents who are experiencing similar challenges and swap stories and vent together—find them at support groups or places like www.meetup.com. Investigate counseling supports through your insurance plan, place of worship or community services agency.

Use the information in this tool kit to seek out information and team members who will support you, and help your loved one to grow to become all he can be. Take small steps, and celebrate the growth and accomplishments along the way. Be the detective that helps you better understand—and hopefully better accept—your child and the difficulties he faces as he goes through life. Use the strategies and resources in this kit and from your team to help you build a place in which everyone feels safer and more successful. Advocate for help when you need it. Find resources or create a plan for respite care so that you get a break too, and use it!

Recognize the resilience your loved one with autism shows each and every day. Celebrate the things he says or does that make you laugh: his dimples, his artwork, his smile. Sure, you may cry or swear sometimes. But also rest. Breathe. And celebrate the successes one at a time, whenever and wherever they come.

“A multidimensional, comprehensive approach to ASD that emphasizes the development of positive, constructive behavior, builds family cohesiveness and mutual support, focuses on successful home and community living, and addresses systemic barriers to progress will not “cure” autism, but it will make it possible to live happily with autism. These goals are realistic and can be achieved now.”

– Ted Carr, Ph.D.,
State University of New York at Stony Brook