The American Academy of Pediatrics (AAP) just published “Out of Home Placements for Children and Adolescents with Disabilities.” This document provides compassionate but incomplete guidance on a difficult decision for families, and presents out-of-home placement as a last resort. Some placements mentioned include Skilled Nursing Facilities, Intermediate Care Facilities, hospitals (including rehabilitation, medical group homes, and transitional facilities), and residential placement. This article will cover alternative placement options including those in the home and community, in a non-judgmental way, and to support families in whatever they decide is best. It is beyond the scope of this article to detail how to access each, but the contact resources listed below can assist families with navigating these systems.

OPTIONS FOR MEDICAL ISSUES
Some states have pediatric and adult daycare. These can be used either short term for someone temporarily medically-fragile, or longer term if the condition is chronic. Medicaid waivers, particularly HCBS (Home and Community Based Services) can also provide supports in the home or community. States that have “Katie Beckett” waivers are based on the premise that it is more cost effective and better for the individual to remain at home if they meet the “institutional level of care” criteria, even if they need 24 hour nursing. Preventable secondary infections lead to serious complications and, in addition to the goal of ensuring a loving home for every child with disabilities, should be the largest reason to avoid congregate care for those who are medically complex. In addition, some states have programs for developmental disabilities that are “self-directed,” in which the consumer and their family decide on services, which could include medical personnel in the home. Other Medicaid programs such as “Cash & Counseling” consumer directed care and other PCA (Personal Care Assistance) programs help individuals with ADLs (activities of daily living) such as personal care, which allows them to remain in their home. Too often Medicaid has had an “institutional” bias when the supports could be better used to keep individuals in their homes and communities. The child shouldn’t be forced to forgo the developmental benefits of a nurturing family and have institutional care as the only option.

OPTIONS FOR MENTAL HEALTH ISSUES
There are options other than the “standard” 28-day stay, which could become a revolving door if the person needs more care. There are “longer” term care facilities which will keep the individual until they recover and are ready to return home. There are also therapeutic day programs for children who may have been hospitalized for mental illness and aren’t ready to return to school.

ANOTHER NEW OPTION
There is another option that honors the child’s developmental needs to grow up in a loving, nurturing family. A number of states have developed the capability for a child’s family to choose an alternative family who would welcome the child into their home and would raise the child with the input of the child’s first family. Alternate families are not part of the Child Welfare System, so there is no judgment made when a parent is no longer able to care for their child. The child shouldn’t be forced to forgo the developmental benefits of a nurturing family and have institutional care as the only option.

Some states fund this option under the name of life sharing, host homes, resource families and shared living. Because there is variation between states in how to access this alternate family service, the state AAP Councils on Children with Disabilities need to be aware of the state agency responsible for life sharing and provide pediatricians with contact information, as well as and how they can assist in making those arrangements – whether it is making a referral, providing documentation of medical needs, etc. While there will be instances when a child is not able to remain at home with their family, pediatricians should promote alternate families as the first and best choice rather than directing families to institutional care. And since institutional care is the very last resort, active planning for a return to family life – either their first family or an “alternate family” – should begin on admission so that the institutional placement is seen from the very beginning as temporary, and not a permanent solution.
KEY CONSIDERATIONS

• Caregiver support is essential to keep individuals at home as more people enter institutional care due to caregiver burnout rather than deterioration of their condition (source: Caregiver Action Network.) The AAP notes that Family Caregivers are providing “more technically demanding care than is possible in many SNFs [skilled nursing facilities], including ventilation and intravenous nutrition, placing substantial responsibilities and stresses on families.”

• Families should visit each program with the individual to decide which best suits their needs.

• There are some medical and other day facilities which have separate programs for individuals with developmental disabilities and eldercare, rather than mixing the population. It is important that individuals are with their peers in an age-appropriate situation. This means that young adults shouldn’t be kept in pediatric placements, nor should they be in nursing homes. Centers for Independent Living have initiatives such as nursing home diversion programs.

• Families and individuals need to visualize what they want as goals to see if the program is a good “fit” and if they can picture the person in that environment.

• Housing is a challenge, but there is now a wide range of options such as accessible apartments, supervised or assisted living, etc.

• Lack of community-based supports and services is the single largest factor in institutional placement.

• Placement with an alternative family is preferable to institutional care.

There is no “one-size fits all” answer and there is a continuum of placement options. Consideration of out-of-home placement is much like special education, which requires examining the Least Restrictive Environment. This is a personal and difficult decision for families and individuals with special needs. Parents need to realize that they are the expert in their child as they are with them all of the time and have a vested interest in the outcome. Shared-decision making is the best approach and including the child or individual to the best of their ability. Self-advocates know what’s best for themselves, and have a great motto – “Nothing about us, without us!”

ABOUT THE AUTHOR:

Lauren Agoratus, M.A. is the parent of a child with multiple disabilities who serves as the Coordinator for Family Voices-NJ and as the central/southern coordinator in her state’s Family-to-Family Health Information Center, both housed at the Statewide Parent Advocacy Network (SPAN) at www.spanadvocacy.org.