Respite for Individuals with Autism

Introduction

Autism spectrum disorders (ASDs) are a group of developmental disabilities that can cause significant social, communication and behavioral challenges. Once thought to be a low incidence disability, the most recent surveillance report from the Centers for Disease Control and Prevention (CDC) says the condition now affects one in 88 children – a 23 percent rise over the 2009 estimate of 1 in 110. Autism occurs along a spectrum with increasing severity in symptoms.

For those individuals on the autism spectrum with significant functional limitations, it can be stressful for their families and result in feelings of isolation within their communities. The physical and mental well-being of parents, siblings and other family caregivers, as well as a family’s social relationships, finances, and overall stability can be affected. Families identify respite care as a basic need, with the need increasing as the child gets older. Respite care for families who have a child or adult with autism helps maintain family stability, has been shown to reduce the probability of hospitalization, and may provide opportunities for the individual with autism to participate in special activities.

This ARCH Fact Sheet is intended to provide a basic overview of useful information for respite providers who work with individuals and families affected by ASD. It is also meant to assist Lifespan Respite grantees and their collaborators by increasing their understanding of the unique needs of this population and their family caregivers. Such insight and direction will help State Lifespan Respite programs and others develop strategies to increase respite quality, access, and capacity for this population through partnerships with community-based services and enhanced provider recruitment and training efforts. It is also intended to offer resources for family caregivers seeking to expand respite opportunities for themselves and others.

What is Autism?

Autism is a complex developmental disability with a variety of symptoms that affect individuals in different ways. It knows no racial, ethnic or social boundaries. People with autism may have difficulties in communication and social understanding. They may also have unusual reactions to sensory input, and may demonstrate what to some people might be considered to be inappropriate behaviors. Autism is now known to be more common than previously thought, affecting as many as 1.5 million individuals nationwide.

While there is still much to learn about autism, basic and applied research have increased a great deal in recent years as a result of efforts of federal agencies and private organizations that are working diligently to better understand autism and better serve the autism community. Just like the many families caring for an individual with autism, these public and private organizations consider autism an urgent public health concern and are undertaking efforts to discover the risk factors and causes, develop treatments and interventions, as well as raise awareness of the signs and symptoms associated with autism. With early and appropriate interventions, followed by ongoing housing,
academic, family and employment supports, an individual with autism can lead a healthy, happy and productive life.

There are five developmental disorders that fall on the autism spectrum and are defined by challenges in three areas: social skills, communication, and behaviors and/or interests (Lord, 2010).

1. **Autistic Disorder** – occurs in males four times more than females and involves moderate to severe impairments in communication, socialization and behavior.

2. **Asperger’s Syndrome** – sometimes considered a milder form of autism, Asperger’s is typically diagnosed later in life than other disorders on the spectrum. People with Asperger’s syndrome usually function in the average to above average intelligence range and have no delays in language skills, but often struggle with social skills and restrictive and repetitive behavior.

3. **Rett Syndrome** – diagnosed primarily in females who exhibit typical development until approximately five to 30 months when children with Rett syndrome begin to regress, especially in terms of motor skills and loss of abilities in other areas. A key indicator of Rett syndrome is the appearance of repetitive movements or gestures.

4. **Childhood Disintegrative Disorder** – involves a significant regression in skills that have previously been acquired, and deficits in communication, socialization and/or restrictive and repetitive behavior.

5. **Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)** – includes children who do not fully meet the criteria for the other specific disorders or those who do not have the degree of impairment associated with those disorders.

NOTE: In 2013, the above diagnostic criteria will change by collapsing some of these categories as a result of the re-write of the Diagnostic and Statistical Manual of Mental Disorders – DSM-V.

The median age of earliest autism diagnosis is between 4.5 and 5.5 years, but for 51–91% of children with autism, developmental concerns had been recorded before three years of age (CDC, 2007). Studies have shown that about one third of parents of children with autism noticed a problem before their child’s first birthday, and 80% saw problems by 24 months (Fombonne, 1998).

Research has shown that a diagnosis of autism at age 2 can be reliable, valid, and stable. But despite evidence that autism can often be identified at around 18 months, many children do not receive final diagnoses until they are much older (Lord, et al., 2006).

**Prevalence and Characteristics**

**Child Prevalence**

The Centers for Disease Control and Prevention (CDC) recently updated its estimate of autism prevalence in the United States to 1 in 88 children. Autism is reported to occur in all racial, ethnic, and socioeconomic groups, yet are on average 4 to 5 times more likely to occur in boys than in girls (1 in 54 boys and 1 in 252 girls) (CDC, 2012).

In the United States, parent-reported data from the 2007 National Survey of Children’s Health indicated an overall estimated prevalence of 11.0 per 1,000 children aged 3–17 years, and data from the National Health Interview Survey demonstrated a nearly fourfold increase in estimated autism prevalence between the 1997–1999 and the 2006–2008 surveillance periods (CDC, 2012).

Studies in Asia, Europe, and North America have identified individuals with autism with an approximate prevalence of 0.6% to over 1%. A recent full population study in South Korea reported a prevalence of 2.6% – approximately one in 38 children (CDC, 2011).

**Adult Prevalence**

Despite the fact that autism is by definition lifelong, there was very little research with respect to the prevalence of adults living with autism until fairly recently. It is expected that in the next decade,
500,000 individuals with autism will turn 21 and are expected to live the average lifespan. In 2009, the National Health Service (NHS) in England released the first ever study of autism in the general adult population. The findings confirmed the assumption that autism is just as common in adults as it is in children. Researchers at the University of Leicester, working with the NHS Information Center found that roughly 1 in 100 adults are on the spectrum – a rate similar to that found for children in England, Japan, Canada and, the United States.

**Characteristics**

All individuals on the autism spectrum do not display the same characteristics. The following characteristics are among the most common:

**Socialization**
- Lack of awareness of others
- Social aloofness
- Lack of cooperative and imaginative play
- Does not imitate
- Does not seek comfort or cuddle as an infant

**Language/Communication**
- Language is not used in a communicative function, instead there may be immediate or delayed echolalia (i.e., what is said to the individual is mechanically repeated); perseveration (i.e., the repeating of phrases of speech over and over); pronominal reversal (i.e., The pronouns “I” and “you” are reversed, so that the individual may say, “You want a cookie,” when s/he desires a cookie)
- Abnormal pitch, rate, rhythm, and/or intonation
- Lack of appropriate nonverbal communication (e.g., eye contact, gestures, pointing, postures)

**Responses to the Environment**
- Self-stimulatory behaviors (e.g., rocking)
- Resistance to change
- Preoccupation with parts of objects, or an attachment to unusual objects

**Behavioral Issues**
- Self-injurious behavior (e.g., head banging, biting)
- Aggression
- Tantrums

**Sensory Responses**
- May appear as if s/he is deaf (e.g. no reaction to very loud noises)
- Stimulus over selectivity (e.g., very sensitive to very soft noises)
- Apparent insensitivity to pain

Many of these characteristics found in childhood may persist into adulthood.

About 40% of children with autism do not talk at all. Another 25%–30% of children with autism have some words at 12 to 18 months of age and then lose them. Others may speak, but not until later in childhood (Gupta, 2004). It is estimated that about 10% of children with autism have an identifiable genetic, neurologic or metabolic disorder, such as fragile X or Down syndrome. As more is learned about genetics, the number of children with autism and an identifiable genetic condition will likely increase (D. Cohen, 2005). A report published by CDC in 2009 reported that 30–51% (41% on average) of the children who had autism also had an intellectual disability (Rice, 2007). One to four percent of people with autism also have tuberous sclerosis (Smalley, 1998).

**Challenges Facing Individuals with Autism and their Family Caregivers**

Being an individual with autism, sibling or a caregiver can often be challenging. From the time of diagnosis, if not sooner, the emotional roller coaster lurches from denial, disbelief, anger, relief (at finally having an explanation for your child’s unusual behavior), guilt, surprise, helplessness, devastation, and then acceptance. Understanding and support is critical during this period.

Having a child diagnosed with autism can lead to difficulties between parents and other family
members. Communication may stop or become limited. This, if not faced head-on and dealt with in a meaningful way, can lead to a breakdown of relationships (Easter Seals, 2008). Dealing with day-to-day life can become exhausting without support such as respite. As the main role in bringing up children usually falls to the mother, they may experience additional emotional stress. This can affect not only relationships between parents, but also performance at work, which can lead to financial effects on the family if working hours and responsibilities must conform to caregiving responsibilities. Grandparents are also similarly affected by a diagnosis of autism within the family and will often worry and experience stress on behalf of the parents.

Due to genetic susceptibility, families who have one child with an autism spectrum disorder face an increased risk of having other children who have cognitive impairments, psychiatric disorders, language delays, and social and communication difficulties (Autism Now, 2012). With increased demands caused by multiple therapy and other appointments, educational and behavioral issues, and the day-to-day stress caused by parenting multiple children who are on the spectrum, families can become overwhelmed.

As children age, more questions surface – What sort of treatment is available? What are the education options? What level of care will be required? How will this affect other siblings, parental relationships and financially, what will the effect be?

Over 75 percent of adults with developmental disabilities live at home with family. A significant number of these family caregivers are over age 60 (over 716,200 older caregivers) and face their own challenges, including age-related functional declines and concerns about what will happen to their relatives when they can no longer provide care (Autism Now, 2012). Although federal law mandates educational services for children with autism, few support services exist once they become adults. Young adults with autism may become

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**Advancing Futures for Adults with Autism**  
http://www.afaa-us.org/site

**Mission:** AFAA is a national consortium of organizations working together, led by the vision of individuals with autism and their families, to promote a collaborative spirit and develop both public and private sector support that improve the lives of adults living with autism.

**Aims:**

- Create and drive public policy change that will support adults with autism to become fully participating members of their communities.
- Lead a national dialogue to increase awareness of the challenges and opportunities for adults with autism to lead full and meaningful lives.
- Be a portal of information on research, programs and services for adults with autism and their families.
- Act as a catalyst in developing strategies and coordinating efforts to improve the quality of services and supports for adults with autism and their families.

**Organizations in the consortium include:** Autism Speaks, New York Center for Autism, Anderson Center for Autism, The Autism Center of Illinois, Autism Treatment Center, Easter Seals, The Homestead, Madison House Autism Foundation, Southwest Autism Research & Resource Center, and Trinity Services, Inc.

To see the national policy agenda of Advancing Futures for Adults with Autism, see: http://www.afaa-us.org/atf/cf/%7B3A65C524-1EB0-4098-97F5-88AB429252C6%7D/AFAA%20National%20Policy%20Agenda.pdf
more isolated as they age out of the educational system and fewer opportunities exist for social and recreational activities. Living independently can pose a challenge with limited housing options and too few post-secondary educational activities or employment options.

For additional resources, see Autism Speaks’ resources for adults with autism at http://www.autismspeaks.org/family-services/resource-library/adults-autism.

**Barriers to Respite**

**Provider Shortages**

Shortages of well-qualified respite providers or flexibility in allowing family caregivers to choose and train their own providers exist for all age groups and conditions, but for children and adults with autism, the challenges of finding respite providers, community supports, or innovative respite programs that can meet their needs can be even more dramatic. Educational awareness about autism has grown tremendously in the last decade, but many providers and community organizations are still hesitant to serve individuals with challenging social and communication behaviors.

Cultural Issues Autism is reported to occur in all racial, ethnic, and socioeconomic groups, although some studies have found that underdiagnoses and referral bias may exist in the medical community (Begeer, S., 2009) However, the most recent CDC surveillance report found that changes in estimated prevalence of autism during 2006–2008 varied by race with statistically significant increases in the prevalence among non-Hispanic white children, among non-Hispanic black children, and a 29% increase among Hispanic children (CDC, 2012).

Cultural differences may exist for how families respond to a family member with autism. Even if parents’ recognize the symptoms of autism, there may be cultural differences regarding what they attribute these symptoms to. As with other intellectual and developmental disabilities, families may attribute symptoms to something other than a health condition. For example, a child’s failure to respond to parental direction may be interpreted as “willfulness” and other behaviors that may fall within the bounds of normalcy. Providers can work with parents to help them understand that symptoms may be indicative of an underlying condition that can benefit from treatment. Acceptance and willingness to use respite may vary among cultural groups, especially if respite providers are not from the same community or cultural background.

**Economic Costs**

Too few resources for families to pay for respite can be a significant barrier to access. Expenses for lifetime care for an individual on the autism spectrum is estimated at $1.4 million. For an individual with autism who also has intellectual disability, lifetime expenses are $2.3 million in the U.S. on average (Knapp and Mandell, 2012).

Individuals with autism have average medical expenditures that exceed those without autism by $4,110–$6,200 per year. On average, medical

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**Easter Seals developed a training curriculum, “Generations & Autism Connect”, a program to enhance the learning of individuals, especially older adults, who will be volunteering with children with autism. “Generations & Autism Connect” is a modular training curriculum. Each module contains a PowerPoint presentation, a script for the presentation, and supporting handouts. Module Topics include: 1) Overview of Autism; 2) Families; 3) Communication; 4) Behavior; 5) Community Integration; 6) Socialization. Pre-post tests are provided for each of the modules. These tests can assess participant learning from didactic instruction. Contact: Patricia Wright, Easter Seals, 233 S Wacker, Suite 2400, Chicago, IL 60606 at 312-551-7226 or pwright@easterseals.com**
expenditures for individuals with autism are 4.1–6.2 times greater than for those without autism. (Rice, 2008) Mothers of children with autism are less likely to work, work fewer hours per week and earn substantially less. Typically the primary caregiver, mothers are called upon to serve as their child’s case manager and advocate, and on average, earn 56 percent less than mothers of children with no health limitations and 35 percent less than mothers of children with another health limitation (Cidav, et al, 2012). Given higher education and medical expenditures than other families, even other families caring for someone with a health limitation, it can be assumed that families of children with autism might find respite to be unaffordable, another barrier to timely access.

Respite for Children
Respite for children with autism is essential for family well-being and the health and safety of the child. In a recent study, University of Pennsylvania researchers analyzed the records of 28,000 children with autism ages 5 to 21 who were enrolled in Medicaid in 2004. They concluded that for every $1,000 states spent on respite services in the previous 60 days, there was an 8 percent drop in the odds of hospitalization, illustrating the tremendous need for respite (Mandell, 2012). Considerations for providers, state agencies, and Lifespan Respite programs trying to fill this gap in respite services for children with autism include issues regarding provider training, retention, and best practices in program implementation.

Provider Training
Respite providers who are working with children with autism should be appropriately trained by the family caregiver or a professional with experience in autism about the characteristics of autism and the types of intervention that will need the specific needs of the child. Because of the breadth of the autism spectrum and the unique characteristics, children with autism typically require specialized therapeutic and educational services. For children with autism who may have challenging behaviors, the ability to deal appropriately with these behaviors is critical to respite provider success and retention. Training should also include information on communication, intensive behavior management, developmentally appropriate instructional strategies, social skills and incidental teaching.

Respite care providers should meet with each family before beginning the provision of respite care to discuss the individual child’s unique routines and established patterns. This helps ensure consistency of care for the child and develops a sense of trust between the family, child, and provider. The need for predictability, structure and routine is a critically important element when providing respite care for children with autism since many children with autism typically insist on sameness. When the environment is altered, they often become anxious, agitated or frustrated.

Program Guidelines
Respite programs which serve children with autism should establish clear and concise routines; set specific times for certain activities, such as snack time, naps, toileting, social activities etc. Consistency is important for this population. Children with autism experience difficulty in learning. Often, they are unable to generalize what they learn across people, settings, or situations. However, if providers are consistent, the children

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**Easter Seals**

Easter Seals respite programs give participants an opportunity to engage in social and recreational activities while their families get a much-needed break from the demands of caregiving. Many of the local Easter Seals affiliates provide respite for children as well as adults with autism. For local programs by state, see http://www.easterseals.com/site/PageServer?pagename=ntl48_autism_service
do not need to spend as much time testing limits.

Respite programs should address the need for behavioral interventions. The worker should be trained directly by the family caregiver and/or a professional who develops a behavioral intervention plan specific for the child. The worker should fully understand their role in managing the specific behaviors of the child with autism. Some examples of positive behavioral interventions that have been successful in remediating behavioral issues (e.g., help with self-help skills) include:

- **Use of redirection:** when children with autism are engaging in inappropriate behavior, redirecting the child to another, more appropriate activity may be effective.

- **Use of rewards:** choose rewards that are meaningful to the child. The rewards must be individualized, and may require some creativity. For example, some children with autism become attached to specific objects, such as a familiar piece of clothing. Extra time with that object could be a reward.

Respite programs should incorporate educational components to assist in completing activities of daily living. Some examples include:

- **Use of clear and simple instructions:** due to attention challenges that children with autism often experience, it is helpful to keep instructions short, clear and concise.

- **Use of prompts:** verbal instructions, gestures, or physical assistance are three prompts that are often used in working with children with autism.

- **Divide tasks into small steps:** For example, if the child was being instructed to pull down his/her pants for toileting, the first step may consist of having the child only grasp the waistband; the second step could be pulling the pants over his/her hips, etc. The child is taught one step at a time, and does not move onto the next step until s/he can successfully complete the previous step.

If family caregivers are hiring their own respite providers, they may prefer to do their own training or specific provider training may be available through local autism resources. Family caregivers and parents may want to consider arranging and/or paying for training for their respite providers through one of these resources. For a list of such resources by state, see the Autism Speaks online Resource Guide at http://www.autismspeaks.org/family-services/resource-guide or the Autism Now Resource Center’s map and directory of local services at http://autismnow.org/map.

Respite for Adults with Autism

Many adults with autism can live independently. However, either by choice or necessity due to the lack of appropriate community-based alternatives many adults with autism live at home, often with aging parents. As parents age, respite may become even more important, but the respite options fewer. Resources are needed to develop model programs that are tailored to serve this population and be meaningful for them.

For an adult with autism, respite can be the bridge to living outside the family by helping to build skills needed for independent living. Out-of-home respite care can enable families to test this option, explore community resources and prepare themselves and their family member with autism to live in the community. Social or recreational activities in mainstreamed settings can help improve peer to peer relationships for young adults with autism and provide respite for family caregivers at the same time. Since specific programs designed for adults with autism may be more difficult to find and training programs also limited, consumer-directed respite that allows family caregivers to select in-home or out-of-home providers or services, and hire and train their own respite workers may provide more options.

At the same time, it is important for parents or other family caregivers to address the question of “What will happen to my child when I’m gone?” The answer – start transition early and, develop an incremental, long-term plan. The center piece of this approach is the creation of a “life plan” which covers a broad range of matters and serves as a reference for those who will be interacting with the individual with autism over the years. The plan should be a source of information about the person with autism and provide a comprehensive guide for the person’s future. The plan is revised routinely or as needed if the circumstances of the consumer, parental caretaker or designated guardian changes. The plan would include information on such things as legal and financial arrangements, medical needs and residential preferences.

While the adult with autism is living at home, components of this plan can also be used to assist the respite provider. If the plan provides details about the person such as food and entertainment preferences, personality, daily routines and description of functional skill levels, it can be shared with the respite provider to provide a safe and meaningful experience.

For more information on life planning, see http://www.foundationforautismsupportandtraining.org/lifePlanning.html. For more information on transitional planning for young adults with autism from the educational system, see Autism After 16’s Roadmaps to Resources at http://www.autismafter16.com/article/03-30-2012/introduction-roadmaps.

Federal Funding Sources

Medicaid Home and Community-Based Services (HCBS) Waivers

There are several different types of state Medicaid waivers, but Medicaid Home and Community-Based 1915(c) Waivers provide funding for supports and services that help individuals with disabilities live in their homes and communities and typically cover respite services. Unlike Medicaid medical assistance, waivers are not an entitlement program and may have long waiting lists so it is very important for families to get information as soon as possible following a diagnosis of autism.

The number of available waivers and the qualification requirements vary from state to state. Most states offer waivers to provide home- and community-based services to people with developmental disabilities (DD), which may cover individuals of all ages with autism. In recent years, many states have added a waiver program specifically for individuals with autism. Currently, there are 10 states with autism-specific waivers: Colorado (0–6), Kansas (0–5), Maryland (1–21), Massachusetts (birth to 8), Missouri (3–18), Montana (1–4), Nebraska (0–17), and North Dakota (birth to 4). Pennsylvania has an adult autism waiver.
that covers individuals with autism who are 21 and older and Indiana’s autism waiver covers all ages. Colorado’s waiver covers only behavioral therapy and Nebraska’s waiver only early intervention therapy services – and not respite.

For information on home and community-based Medicaid Waivers by state, visit the ARCH National Respite Locator at www.respitelocator.org and click on a state or see ARCH’s Compendium of Home and Community-Based Medicaid Waivers that Pay for Respite at http://archrespite.org/productspublications/products-and-publications#Waivers.

**Children’s Health Insurance Program (SCHIP)**

Each state has a Children’s Health Insurance Program that provides free or low-cost health insurance for eligible children. Insure Kids Now! is a national campaign sponsored by the US Department of Health and Human Services to link the nation’s 10 million uninsured children from birth to age 18 to free or low-cost health insurance. The website has basic facts about these programs as well as links to every state’s program for children. (U.S. Department of Health and Human Services, 2012) Currently, only a few states include respite as a benefit in the SCHIP program (Dougherty, 2012).

**Supplemental Security Income (SSI)**

This is a cash benefit program. Direct monthly payments are available for unrestricted use, including for respite, for those with incomes and resources below certain levels who are blind, have disabilities, or are age 65 or older. Under the age of 18, eligibility is based on parents’ income. Over the age of 18, eligibility is based on the income of the person who has a disability.

**Lifespan Respite Programs**

Funding is limited, but at least one-third of the 30 State Lifespan Respite programs funded by the US Administration on Aging are providing direct services or supporting respite through vouchers or other consumer-directed options. In 2011, seven states and the District of Columbia received expansion grants to focus on service delivery, especially for underserved or unserved populations. These state Lifespan Respite programs are just two examples of those funding respite for individuals with autism:

* Alabama Lifespan Respite Resource Network contracts with the Alabama Department of Mental Health (DMH) and historically has received grants from the Alabama Department of Child Abuse and Neglect and Prevention, Children’s Trust Fund (CTF) to provide vouchers for caregivers to receive respite services. For a caregiver to qualify to receive a voucher funded by DMH, the individual who has autism must also have an intellectual delay, but can be any age. To qualify for a CTF voucher, the child must be under 19 years of age with a diagnosis of autism. For specifics on Alabama’s voucher program and for program contact information, see the ARCH Guide to Participant-Directed Respite at http://www.lifespanrespite.memberlodge.org/Resources/Documents/RespiteGuidebookFinal6.pdf.

* Tennessee Respite Coalition with funding from the TN Department of Mental Health provides vouchers for caregivers of children with autism who live in families with an annual household income under $40,000. If the family’s income is over that limit, but the family is still in need or the care recipient is over age 18, other voucher funding sources are explored, including funds from the Lifespan Respite grant. For more information, contact the Tennessee Respite Helpline at 1-888-579-3754 or visit www.tnrespite.org/services.

For more information on State Lifespan Respite grantee activities, see http://archrespite.org/ta-center-for-respite/webinars-and-teleconferences/webinar-lifespan-respite-101#GranteeActivities.
State Funding Sources

State Family Support Services

Family support programs for children and/or adults with developmental disabilities exist to varying degrees in the states. Family support services may be defined differently in states and localities, but generally they provide a coordinated system of services, resources, and other assistance for families caring for individuals with developmental disabilities who live at home. Services may include, but are not limited to, in-home and out-of-home respite, cash stipends, assistive devices, recreation and social programs. Some states include any service defined by the family. Funding is typically modest and subject to waiting lists. For more information, see ARCH’s State Funding Streams for Respite at http://archrespite.org/productspublications/products-and-publications#StateFunding.

State-Funded Specific Autism Programs

In some states, the mental health or developmental disabilities agency may provide specific state funded autism services. An example is:

- Missouri. The Department of Mental Health’s Division of Developmental Disabilities funds five regional autism projects that collectively provide services to approximately 2500 families statewide. Individuals are referred to their autism projects through their regional office. The programs and services are designed to assist in skill development of individuals with autism and provide needed training and support, including respite, for families. The first project was established in 1991 as a result of families in rural Missouri approaching legislators to ask for autism-specific family support. They requested needed services so that their family members could remain at home and receive supports close to home. The 5 Missouri Autism Projects are overseen by the Missouri Advisory Committee on Autism and by Regional Parent Advisory Councils. http://dmh.mo.gov/dd/autism/AutismProjects.htm.

Issues for State Lifespan Respite Programs and other Program Administrators

Respite care for families of children with autism provides assistance through the provision of emergency and planned care as well as access to other family support services. Yet it is not always readily available or affordable in the community and there is a shortage of qualified and well-trained providers. Too few respite programs are equipped specifically to deal with the unique needs of this population. As children with autism age out of the education and health systems that may serve them, even fewer respite or other opportunities for support or assistance exist for them and their families.

Improved Education and Training for Respite Providers

It is essential that education and training opportunities be made available to those providing respite for individuals with autism. Because many of the symptoms of autism are behavioral, many family caregivers may be particularly concerned about leaving their loved one with a respite provider who is not educated about autism. Ensuring that respite providers have specific knowledge regarding autism and behavioral health issues may make it easier for family caregivers of individuals with autism to utilize respite care and get a much needed break from their caregiving duties.

Maximize Flexibility and Consumer Control

Not all family caregivers have the same respite care needs. A great deal of diversity exists among family caregivers. They may have very different family relationships, caregiver resources and stressors, care recipient needs, and caregiving responsibilities. Therefore, a wide array of policy and programmatic options are needed to address these diverse needs. Efforts should be made to match the individual family need with available services or develop new services to meet caregiver needs (Autism PDD Support Network, 2010).
Promote Culturally and Linguistically Competent Care

The U.S. population is becoming increasingly racially and ethnically diverse. The latest report from CDC now indicates significantly higher rates of autism in Hispanic and Black populations. Layered on top of issues related to the difficulty of finding and paying for respite for this population, a failure to address cultural needs of families may add another barrier to respite access.

Issues for Family Caregivers

Family caregivers of children or adults with autism face many of the same barriers to respite that other family caregivers face. However, the supply of respite providers who are adequately trained to understand how to deal with unique behaviors of individuals on the spectrum may be even more limited than for other populations. This is especially problematic for individuals with autism, who are even more dependent on consistent routines for their well-being and stability and require consistency in providers. High provider turnover can make respite prohibitive for their family caregivers. Simply put, a good respite care provider is worth their weight in gold. Finding, hiring and keeping qualified respite providers is difficult, especially as children with autism age out of currents systems of support, and have fewer social and recreational opportunities that might have served as respite as a child.

Recommended Strategies

Expanding respite options and improving respite access, appropriateness, acceptance and cultural relevance for those caring for children and adults with autism will require the expertise of individuals who work in the field of developmental disabilities services and experts, advocates, government agencies, community providers and many others diligently working in partnership with family caregivers. There are steps that Lifespan Respite Programs, respite coalitions, respite providers and family caregivers can take to improve the situation.

Agape Respite Center, Berne, Indiana

Established in 1992, Agape Respite Care, Inc. continues to provide short term care across the lifespan for children and adults with physical or intellectual disabilities. Agape provides in-home, out-of-home and emergency respite for individuals of all ages so that families do not have to transition to a new respite provider as individuals age. Any individual with an intellectual and/or physical disability or chronic health condition can be served. A significant number of respite guests have challenges due to Autism, Asperger’s Syndrome, Rett Syndrome or Pervasive Developmental Delay. Staff is trained in providing personalized care to meet the personal health and safety needs as well as engage them in activities for their personal enjoyment. Respite care hours are available 24 hours a day, 7 days a week. A stay may be from a minimum of two hours to a maximum of ten consecutive days not encompassing more than one weekend. Stays must include an approved plan of care and an emergency back-up plan with specific contacts in the absence of the parent or guardian. Payment options include Indiana Medicaid Waivers; Ohio Home Care Waiver; Family Caregiver support Program; C.H.O.I.C.E. Program and private pay. Families are assisted in applying for subsidy programs to cover the cost of respite care or payment is on a sliding fee scale according to family size and household income. Agape is committed to serving needs and will not turn someone away because of their financial situation. Agape Respite Care is certified by the Indiana Family Social Service Administration, Division of Disability and Rehabilitative Services and nationally accredited by the Council on Quality and Leadership. For more information, visit http://www.agaperespite.org/default.aspx.
For State Lifespan Respite Programs

Lifespan Respite programs should ensure that they are identifying available services, as well as gaps in services for this population, and targeting training and recruitment resources to help meet the need for this population.

1. Efforts must be made to develop and maintain a culturally and linguistically competent workforce of individuals to care for the needs of those with autism and their families. This includes respite providers and others who provide services and supports to family caregivers.

2. Grantees, charged with public education and education of family caregivers, can take the lead in bringing experts together to develop public awareness and education materials that focus on the special needs of adults with autism.

3. While conducting needs assessments in your states to identify service gaps, include questions to determine the specific barriers to respite for this distinct population and work toward strategies to overcome these barriers.

4. In developing training materials to recruit and train respite providers and volunteers, seek expertise from the professional community who work in the field of developmental disabilities and autism and family caregivers to develop training modules that will result in more respite providers able to serve this population. Include family caregivers as part of the training team for professionals.

5. Offer participant-directed respite so that family caregivers have greater choice in hiring and training their own providers from their trusted communities of support.

6. Train family caregivers to recognize the warning signs of burnout and how to recognize when they might be in need of additional care themselves.

7. Develop training programs for peer mentors to assist other family caregivers. They understand what others caring for someone with autism are experiencing.

For Respite Programs, Community Agencies, and Health Care Providers

1. Some respite programs allow family caregivers to make key decisions about the type of services their loved ones will receive and who will provide those services. While some programs designate that respite must be provided by an agency provider or an independent provider who is not a family member, others allow family members, relatives, or friends to serve as providers of paid respite care.

2. When looking for volunteers to assist in respite service delivery, consider reaching out to university or community college students who are pursuing careers in the developmental disabilities field or look to state autism organizations to find and train volunteers.

3. Develop and use training modules that educate the respite workforce in the special needs of individuals with autism and offer additional supports to encourage respite workers to engage with this population.

4. Include family caregivers, individuals with autism, and advocates in the development and implementation of respite services.

For State Respite Coalitions

1. Partner with autism organizations, services and advocates, including self advocates, to provide information sessions for family members focused on particular aspects of autism, what to expect, and how to seek support.

2. Partner with autism organizations, service providers and advocates, including self-advocates, to raise awareness about autism and the need for services.

3. Advise the state Lifespan Respite Program in identifying gaps in respite services for this population and work with them to address gaps in services for children and adults with autism.
For Family Caregivers

1. Families can, and should, seek information and guidance from their local Autism Society chapter. Parents who have “been there and, done that” can provide a wealth of information and support when it comes to finding and paying for respite.

2. Become involved with your State Respite Coalition and/or your State Lifespan Respite Program to share input regarding your specific respite needs.

3. If your state programs are already working on these issues, stay involved to offer your expertise and input as new respite services are developed and new providers are trained and recruited.

4. Seek support and use respite early and as often as appropriate!

Conclusion

The prevalence of autism spectrum disorders appears to be on the rise with 1 in 88 children being diagnosed annually. More is being learned about the health, emotional, social, and treatment aspects of autism across the spectrum. Still, too few supports for individuals and their families are available to ensure the health and well-being of the entire family and too few services for adults with autism living at home or in the community exist. Respite is especially important for family caregivers of children and adults with autism as it provides the relief that can help sustain their own health and the well-being of the entire family. But respite can also help provide social and recreational activities for many adults with autism and be a bridge to the community by helping to build skills needed for independent living.

Resources

The following resources may be helpful to Lifespan Respite Programs, respite providers, individuals with autism and their family caregivers.

ARCH National Respite Locator. Families, care coordinators, providers and others can search for respite for children and adults with autism in their local communities as well as for state and federal funding sources, eligibility criteria and contact information at www.respitelocator.org.

Autism Now! The National Autism Resource and Information Center is a project of national significance funded through the Administration on Developmental Disabilities. The Arc of the U.S. hosts the site dedicated to providing quality resources and information for individuals with Autism Spectrum Disorders (ASD) and other developmental disabilities, their families, and other targeted key stakeholders, including underserved and unserved. Focus areas include Early detection, Early intervention, and Early education; Transition from high school into early adulthood; Community based employment; Advocacy for families and self-advocates; Community Inclusion; Aging Issues; Policy; Implementation of Health Care Reform, including Long Term Care Services and Supports; Family and Sibling Support; and Networking in local, state, and national arenas. http://autismnow.org Information & referral call center 1-855-828-8476.

Autism After 16 is dedicated to providing information and analysis of adult autism issues, with the emphasis on analysis. http://www.autismafter16.com/content/about-us

Autism Society of America is a grassroots autism organization that works to improve the lives of all affected by autism by increasing public awareness about the day-to-day issues faced by people on the spectrum, advocating for appropriate services for individuals across the lifespan, and providing the latest information regarding treatment, education, research and advocacy. www.autism-society.org

Autism Speaks is one of the nation's largest autism science and advocacy organization dedicated
to increasing awareness of autism spectrum disorders and to funding research into the causes, prevention and treatments for autism. http://www.autismspeaks.org

The Autistic Self Advocacy Network is a 501(c)(3) nonprofit organization run by and for Autistic people. ASAN’s supporters include Autistic adults and youth, cross-disability advocates, and non-autistic family members, professionals, educators and friends. ASAN was created to provide support and services to individuals on the autism spectrum while working to educate communities and improve public perceptions of autism. Our activities include public policy advocacy, community engagement to encourage inclusion and respect for neurodiversity, quality of life oriented research, and the development of Autistic cultural activities. http://autisticadvocacy.org/about-asan

Association of University Centers on Disabilities (AUCD) is a membership organization that supports and promotes a national network of university-based interdisciplinary programs http://www.aucd.org. AUCD maintains the Interdisciplinary Technical Assistance Center (ITAC) on Autism and Developmental Disabilities to improve the health of infants, children, and adolescents who have, or are at risk for developing autism and other developmental disabilities. The Center accomplishes this by providing technical assistance to interdisciplinary training programs (i.e., the LENDs and Developmental-Behavioral Pediatrics (DBP) programs) to better train professionals to utilize valid and reliable screening tools to diagnose or rule out and provide evidence-based interventions for children with autism and other developmental disabilities. http://www.aucd.org/itac/template/index.cfm

Easter Seals is one of the nation’s leading providers of services and support for children and adults living with autism and their families. Their site includes state by state information and resources on autism. http://www.easterseals.com/site/PageServer?pagename=ntlc8_autism101

Health Resources and Services Administration (HRSA) is an agency of the U.S. Department of Health and Human Services. HRSA is the primary Federal agency for improving access to health care services for people who are uninsured, isolated or medically vulnerable. Congress reauthorized the Combating Autism Act in 2011, a law that strengthened support and coordination for federal research, professional training, and the development of interventions for autism. HRSA spearheaded various efforts arising from passage of the original legislation in 2006. HRSA’s autism initiative is also funding professional training grants to two interdisciplinary leadership education initiatives and a resource center, grants for state demonstration and policy programs in nine states, a State Public Health Coordinating Center to improve access to health care and services to children with autism, two large autism intervention research networks and seven research grant programs in several states. http://mchb.hrsa.gov/programs/autism/index.html

Interagency Autism Coordinating Committee (IACC) is a Federal advisory committee that coordinates all efforts within the Department of Health and Human Services (HHS) concerning autism spectrum disorder (ASD). Through its inclusion of both Federal and public members, the IACC helps to ensure that a wide range of ideas and perspectives are represented and discussed in a public forum. http://iacc.hhs.gov; http://health.nih.gov/topic/Autism

The National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC). The Children’s Health Act of 2000, passed by Congress and signed into law by former President Clinton, required the establishment of the NCBDDD at CDC. In April 2001, NCBDDD was officially established. The Center is heavily involved in public awareness activities, surveillance, and prevention activities. The Center maintains a wealth of information through the Autism Resource Center. http://www.cdc.gov/ncbddd/autism/index.html
References


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