



## Respite for Individuals with Autism



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### Introduction

Autism is a neurological and developmental disorder that can cause significant social, communication, and behavioral challenges. Once thought to be a low incidence disability, the most recent report from the Centers for Disease Control and Prevention (CDC) says the condition now affects 1 in 36 children – a 211% rise over the 2009 estimate of 1 in 110.

For those individuals with Autism with significant functional support needs, 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 an overview of useful information for respite providers who work with individuals and families affected by Autism. 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 1 in 36 children, and over 5 million adults. (CDC, *Data & Statistics on Autism Spectrum Disorder, 2023*; Dietz, et al., 2020).

While there is still much to learn, 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 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.

According to the Autism Society of American, “Autism Spectrum Disorder, hereafter referred to as, Autism (which includes Asperger’s Disorder and Pervasive Developmental Disorder – Not Otherwise Specified [PDD-NOS]), is a complex, lifelong developmental condition that typically appears during early childhood and can impact a person’s social skills, communication, relationships, and self-regulation. The Autism experience is different for everyone. It is defined by a certain set of behaviors and is often referred to as a “spectrum condition” that affects people differently and to varying degrees.” It has been estimated that between 25–70% of people with Autism meet criteria for having an intellectual and developmental disability (Autism Research Institute, n.d.).

While there is currently no known single cause of Autism, early diagnosis helps a person receive resources that can support the choices and opportunities needed to live fully. The average age of earliest Autism diagnosis is just under 4.5 years, but for 85% of children with Autism, developmental concerns had been recorded before three years of age (CDC, 2018). 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 (CDC, *Screening and Diagnosis of Autism Spectrum Disorder*, 2022).

### **Child Prevalence**

The Centers for Disease Control and Prevention (CDC) recently updated its estimate of Autism prevalence in

the United States to 1 in 36 children (Maenner, et al., 2023). Autism is reported to occur in all racial, ethnic, and socioeconomic groups, yet boys and men are 3 times more likely to be diagnosed with Autism than girls and women (Loomes, et al., 2017).

Global research estimates that worldwide, about 1 in 100 children has Autism, though this number is likely due to underreporting (WHO, 2023).

### **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. Recent research estimates that over 2% of adults in the U.S. have Autism, supporting findings that Autism rates among adults are similar to those among children. Similar demographic trends emerge among adults with Autism to trends among children with Autism, with men being diagnosed at higher rates than women (Dietz, et al., 2020).

### **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 are 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 Autism face an increased risk of having other children who have cognitive impairments, psychiatric disorders, language delays, and social and communication difficulties (Cleveland Clinic, 2023). 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 with Autism, families can become overwhelmed.

As children age, more questions surface. What sort of interventions are 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?

Approximately 60% of adults with intellectual and developmental disabilities (IDD) live at home with family. This number represents those receiving Long-Term Services and Supports and may not represent the full numbers of adults with an IDD. A significant number of these family caregivers are over age 60 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 (Larson et al., 2022).

Although federal law mandates educational services for children with Autism, few support services exist once they become adults. Young adults with Autism may become 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 on adults with Autism, see [Autism Research Institute's resources](#) for adults with Autism or the Autism Society of America's [Autism Source](#), a comprehensive database of services nationwide.

## Benefits of Respite

Respite for children with Autism is essential for family well-being and the health and safety of the child. Among its benefits, respite can provide social, recreational, and life-skills development opportunities for autistic children and adults.

Respite may even help reduce the likelihood of psychiatric hospitalization of children with Autism.

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% drop in the odds of hospitalization (Mandell, et al., 2012).

Respite has also been shown to benefit parental well-being and enhance family stability. One research study found single mothers of a child with Autism who used respite reported fewer symptoms of depression (Dyches, et al., 2016). Another study found the number of hours of respite care for parents of a child with Autism was positively related to improved marital quality for both

### TRE-ADD Respite Choices of Community Living Toronto, Canada

TRE-ADD Respite Choices of Community Living Toronto offers year-round flexible short-term respite care for both children and adults living with a family caregiver. The care can be provided for a few hours, a few days, or up to a week depending on the individual's needs.

The program consists of a multi-disciplinary team that includes a respite coordinator, behavior services consultant, program manager, supervisor, and support workers. They collaborate with other community professionals including school staff, teachers, psychiatrists, general practitioners, pharmacists, speech and language pathologists, and occupational therapists.

In addition to the short-term respite care, the Respite Choices Program also provides a selection of both overnight and day camps and after-school programs for individuals with intellectual disabilities. TRE-ADD Respite Choices was recognized by ARCH as an [Innovative and Exemplary Respite Service](#).

Before scheduling respite care, individuals must complete a short (3-4 hours) observation session with the person attending respite along with a tour of the respite center and an intake package. For more information about the program, visit their [website](#), call 647-729-0450 or email [respitchoices@cltoronto.ca](mailto:respitchoices@cltoronto.ca).

husbands and wives (Harper, et al., 2013). Parents in active-duty military families receiving respite reported less stress, anxiety, and depression (Christi, et al., 2022). In an integrated review of respite care among caregivers of children with Autism, most of the studies reviewed found that respite care was associated with lower stress among caregivers (Whitmore, 2016).

## Need for Respite

An analysis of data from the 2009–2010 National Survey of Children with Special Health Care Needs (CSHCN) found that the prevalence of unmet respite care needs in parents of children with Autism was seven times higher than parents of CSHCN without Autism. The author concluded that screening all parents of CSHCN for unmet respite care needs is important, recognizing that parents of children with Autism, functional limitations and high caregiving demands are at highest risk for unmet respite care needs (Whitmore, 2017). Little is known about the respite needs among caregivers of adult children with Autism. However, as the availability of supports generally declines in adulthood while the caregiving demands for someone with Autism may not, assumptions can be made that respite remains a high unmet need.

Without appropriate services and clear pathways to support such as respite, overwhelmed parents and the health professionals who support them may not be meeting the needs of children with Autism, resulting in increased hospitalizations (Cooke, et al., 2020).

## Barriers to Respite

Despite the well-documented benefits of and need for respite care for individuals with Autism and their families, persistent barriers to accessing services remain.

### 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 two decades, but many providers and community organizations are still hesitant to serve individuals with challenging social

and communication behaviors, or know where to refer families for specialized services and supports.

### Cultural Issues

Autism is reported to occur in all racial, ethnic, and socioeconomic groups. However, the most recent CDC community report on Autism found that a higher percentage of Black, Hispanic, and Asian or Pacific Islander (A/PI) children were diagnosed with Autism compared with White children. (CDC, 2023).

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 Considerations

Too few resources for families to pay for respite can be a significant barrier to access. Expenses for lifetime care for an individual with Autism is estimated to fall between \$1.4 million and \$2.4 million (Buescher, et al., 2014). Children with Autism have average yearly medical expenditures between \$6,467 and \$18,106 per year, and adults with Autism have average yearly medical

### Easterseals

Easterseals 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 Easterseals affiliates provide respite for children as well as adults with Autism. For local programs by state, visit [the website](#).



expenditures ranging from \$13,580 and \$27,159. Mothers of children with Autism are less likely to work, work fewer hours per week and earn substantially less. Typically, mothers, who are most frequently the primary caregivers, are called upon to serve as their child's case manager and advocate, and are often forced to drop out of the workforce to fill the caregiver role (Buescher et al., 2014). 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 with Autism

The following issues should be considered when designing or implementing respite services for children with Autism.

### 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 meet the specific needs of the child. Children with Autism typically require specialized therapeutic and educational services. For children 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, positive behavioral supports, developmentally appropriate instructional strategies, social skills, and incidental teaching. See more about how to make informed decisions about appropriate interventions and therapies on the Autism Society [website](#), including a [resource](#) on understanding and navigating applied behavior analysis ABA.

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.

## WHO eLearning Caregiver Skills Training for Families of Children with Developmental Delays or Disabilities, including Autism

This training, developed by the World Health Organization in collaboration with international partners, provides easy to use e-learning modules that teach strategies to parents and other caregivers to use at home with children with Autism and other developmental delays or disabilities.

At no cost to families, the evidence-based CST program teaches parents and caregivers the day-to-day skills they need to help children reach their full potential. Caregivers are taught to use everyday play and home routines as opportunities to build their child's communication, engagement, positive behavior and daily living skills.

Parents and caregivers also learn essential problem solving and self-care skills to build confidence, reduce stress and improve their overall well-being – all while learning how to better support their children. [Learn more and enroll](#) in the training.

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 have difficulty learning. Often, they are unable to generalize what they learn across people, settings, or situations. However, if providers are consistent, the children 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, or call the Autism Society's information line at (800) 328-8476.

For a checklist of what to look for when searching for respite for children with Autism, see [Autism Speaks: A Parent's Guide to Autism](#) or visit ARCH's [How to Choose a Respite Provider](#).

### Autism Society of Greater Wisconsin

With funding from the Respite Care Association of Wisconsin (RCAW), the Autism Society of Greater Wisconsin partnered with the Building for Kids Children's Museum and Wisconsin Early Autism Project to host a [respite care program](#) for children with Autism and their families. Through the program, children with Autism and their siblings ages 3–12, are welcomed for a night of play and discovery at the Building for Kids Children's Museum, while caregivers have the night to take care of themselves. Experienced staff from Wisconsin Early Autism Project play with and guide small groups of children through the museum exhibits, ensuring a fun and engaging evening for all. Dinner and snacks are provided for the children and the event is free for families, with support from RCWA. The Autism Society of Greater Wisconsin organized the event, facilitated sign up, and communicated with both families and partners.

### Northern Nevada R.A.V.E. Family Foundation *Respite And Volunteer Experiences*

The mission of the Northern Nevada R.A.V.E. Family Foundation (RAVE) is to improve the well-being of Nevada families by providing respite to families caring for children and young adults ages 3 months to 22 years with disabilities, including Autism, special health care needs, and children in foster care. Siblings are also served. RAVE is a non-profit organization that trains youth volunteers to help provide care in a center-based setting and out in the community. RAVE currently has three respite programs available in order to accomplish this mission: 1) RAVE Family Center, 2) Jr. RAVE, and 3) Teen RAVE. Read more about this unique program on their [website](#), and watch the ARCH [webinar](#).

## 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 often becomes even more important, but respite options are fewer. Resources are necessary 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 mainstream 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 their future. The plan is revised routinely or as needed if the circumstances of the consumer, parental caregiver, or designated guardian change. 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.

### The Daniel Jordan Fiddle Foundation Adult Autism Programs at the Ridgewood New Jersey YMCA

Multiple recreational programs for young adults and adults living with Autism have been and implemented by The Daniel Jordan Fiddle Foundation and the Ridgewood New Jersey YMCA. *Danny’s Red Ball Weekends* provide the opportunity for families of young adults and adults living with Autism to participate in family respite weekends at the YMCA’s Camp Bernie. These weekends are designed to be mini-vacations for families where they can pursue an array of seasonal activities, socialize, and relax with the support of the YMCA staff. For more information on the programs sponsored by the Daniel Jordan Fiddle Foundation, visit the [website](#).

The Children’s Hospital of Philadelphia Research Institute’s CAR Autism Roadmap provides [information on life planning](#) for adults with Autism. The Autism Society also offers resources for [future and financial planning](#).

## Federal Funding Sources for Respite

### Medicaid Home and Community-Based Services (HCBS) Waivers

There are several different types of state Medicaid waivers that 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, which may cover individuals of all ages diagnosed with Autism. In recent years, many states have added a waiver program specifically for individuals with Autism. Currently, there are six states with Autism-specific waivers: Connecticut

(3+), Kansas (0–5), Maryland (1–21), Massachusetts (birth to 8), and North Dakota (birth to 11). Pennsylvania has an adult Autism waiver that covers individuals with Autism who are 21 and older.

For information on home and community-based Medicaid Waivers by state, visit the [ARCH website](#).

### **Tricare**

Tricare provides health insurance services to members of the military and includes specific programs to help provide care for children with Autism. Military families have unique needs and Tricare works with families to develop comprehensive care plans for their children.

The TRICARE Comprehensive Autism Care Demonstration covers the cost of applied behavior analysis services, which are authorized to target the core symptoms of Autism. To qualify for the program, a child has to be diagnosed by an approved diagnosing provider, who must send a referral to a regional contractor or US Family Health Plan (USFHP) provider for authorization. It's important to note that these services are only available in locations with board certified behavior analysts. The authorization letter covers six months of services, and a new reauthorization is required every two years.

This program also provides each family an Autism Services Navigator who can help find and coordinate non-clinical resources, such as respite care. For more information, read more about the Tricare Comprehensive Autism Care Demonstration on the [website](#).

### **Lifespan Respite Programs**

Funding is limited, but most of the current State Lifespan Respite programs funded by the US Administration for Community Living are helping families pay for respite through respite voucher programs or other self-directed options. Lifespan Respite Care grantees may also support volunteer or faith-based respite services that offer free or low-cost respite care.

Contact information to apply for Lifespan Respite voucher programs can be found on the [ARCH website](#). If your state has a Lifespan Respite Care Program or State Respite Coalition partner, you can find contacts on the [U.S. map](#).

## **State Funding Sources for Respite**

### **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. Contact your [State disability agency](#) for more information.

### **State-Funded 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 4,000 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 five Missouri Autism Projects are overseen by the Missouri Advisory Committee on Autism and by Regional Parent Advisory Councils. Visit the [website](#) for more information.

For additional state resources visit the Interagency Autism Coordinating Committee [website](#).



## Private Funding to Support Respite Services

Some local or state affiliates of organizations such as **Easterseals**, **The Arc**, and the **Autism Society** may offer respite funding assistance or services on a sliding fee scale.

For more information about funding sources for respite, visit [How to Pay for Respite](#) on the ARCH website.

## Considerations for State Lifespan Respite Programs, Partners 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.

Primary considerations for providers, state agencies, and Lifespan Respite programs trying to fill this gap in respite services for children and adults with Autism include issues regarding provider training, cultural and linguistic competence, and best practices in program implementation.

### *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.

### *Flexible Person and Family-Centered Services*

A great deal of diversity exists among family caregivers. They may have very different family relationships,

cultural and linguistic preferences, 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's need with available services or develop new services to meet caregiver needs.

### *Culturally and Linguistically Competent Services*

The U.S. population is 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 and linguistic needs of families may add another barrier to respite access.

### *Recommended Strategies for Building or Enhancing Respite for Individuals with Autism*

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.

Lifespan Respite programs and their partners as well as service providers 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 and partners, charged with public education and education of family caregivers, can take the lead in bringing experts together, including Autism organizations, service providers and self-advocates, to develop public awareness and education materials that focus on the special needs of adults with Autism.

3. 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.
4. 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.
5. 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.
6. Offer self-directed respite so that family caregivers have greater choice in hiring and training their own providers from their trusted communities of support.
7. 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.
8. Include family caregivers, individuals with Autism, and advocates in the development and implementation of respite services.
9. Train family caregivers to recognize the warning signs of burnout and how to recognize when they might need additional care themselves.
10. Develop training programs for peer mentors to assist other family caregivers. They understand what others caring for someone with Autism are experiencing.

### Considerations 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 these individuals 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. Finding, hiring, and keeping qualified respite providers is difficult, especially as children with Autism age out of current systems of support, and have fewer social and recreational opportunities that might have served as respite when they were younger.

### Recommended Strategies

1. Families can, and should, seek information and guidance from their local [Autism Society affiliate](#). 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. Parent-run organizations, such as [Family Voices](#) and [Parent to Parent](#) offer resources and support as well.
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! Find more information about types of respite care, and how to find, plan for, choose and pay for respite care on the [ARCH website](#).

### Conclusion

The prevalence of Autism appears to be on the rise with 1 in 36 children diagnosed with Autism. More is being learned about the health, emotional, social, and treatment aspects of Autism. 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 Resources for Family Caregivers.** Find more information about types of respite care, and how to find, plan for, choose and pay for respite care, visit [Caregiver Resources](https://archrespite.org/caregiver-resources/) on the ARCH website. <https://archrespite.org/caregiver-resources/>

**ARCH National Respite Locator Service (NRLS).** Families, care coordinators, providers and others can search for respite for children and adults with Autism in their local communities at using the NRLS. <https://archrespite.org/caregiver-resources/respitelocator/>

**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. Website: <https://Autismsociety.org/>

**Autism Speaks** is one of the nation's largest Autism science and advocacy organization dedicated to increasing awareness of Autism and to funding research into the causes, prevention, and treatments for Autism. Website: <https://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. Their 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. Website: <https://autisticadvocacy.org/>

**Association of University Centers on Disabilities (AUCD)** is a membership organization that supports and promotes a national network of university-based interdisciplinary programs. AUCD supports Autism CARES programs, including interdisciplinary training

programs, such as the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) and Developmental-Behavioral Pediatrics (DBP) programs. Website: <https://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. Website: <https://www.aucd.org/itac/template/index.cfm>

**Easterseals** 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. Website: <https://www.easterseals.com/support-and-education/living-with-Autism/>

**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. Through the Autism Cares Act of 2019, HRSA supports: 1) Training the healthcare workforce to screen, refer, and provide services for children and youth with Autism Spectrum Disorder (Autism) and Developmental Disabilities (DD); 2) Research about Autism/DD interventions and how to best put findings into practice; and 3) Coordinated and effective systems of services that state public health agencies can build for people with Autism/DD and their families. Website: <https://mchb.hrsa.gov/programs-impact/Autism>

**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. 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. Website: <https://iacc.hhs.gov>

**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. Website: <https://www.cdc.gov/ncbddd/Autism/index.html>

**The Arc** is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families. The organization encompasses all ages and all spectrums including Autism, Down syndrome, Fragile X and various other developmental disabilities. To find a local or state chapter go to [thearc.org/find-a-chapter](http://thearc.org/find-a-chapter).

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**Layout:** Norma McReynolds, Graphic Designer

**Acknowledgments:** ARCH would like to thank Kim Musheno with the Autism Society of America and member of the ARCH Advisory Committee for her thoughtful review of the document.

This publication was supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$1,647,597 with 75 percentage funded by ACL/HHS and \$549,200 amount and 25 percentage funded by non-government source(s). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.

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