

Leisure time!

One of the gifts of childhood is leisure time over summer vacation. That's when children discover new interests, learn new skills, and make new friends. In a safe and supportive environment, children can also experience independence and risk-taking.

"All these factors are important to children with autism," notes Heidi Mizell, Autism Delaware's resource coordinator in New Castle County. "I suggest you do a little research, see if a program is something your child might be interested in, and then talk to the program coordinator to make sure your child's needs can be met."

For some questions to ask a program coordinator, see the article, *Considering summer camp*.

The following list includes some programs to consider for your child:

Autism Delaware

Summer day camp, swim, golf

Milton DE: (302) 644-3410
autismdelaware.org

Teen/Tween game night

Newark DE: (302) 224-6020
Milton DE: (302) 644-3410
autismdelaware.org

Camp Atlantic

Delaware program, McLean VA
(703) 863-9485; campatlantic.org

Dragonfly Forest, Inc.

Conshohocken PA
(610) 298-1820; dragonflyforest.com

Camp Fairlee Manor

Chestertown MD
(410) 778-0566; de.easterseals.com

United Cerebral Palsy of Delaware

Camp Manito

(302) 764-2400
ucpde.org/summer-camps

Camp Lenape

(302) 335-5626
ucpde.org/summer-camps

Mary Campbell Center

Karleen O'Brien, Director of Children and Youth
(302) 762-6025
marycampbellcenter.org

Camp Barnes

Special Olympics, Newark DE
(302) 831-3480; sode.org

Variety Club

Rockland DE
(302) 397-0017; varietyphila.org

How would you like to enjoy leisure time yourself this summer?

"Caring for someone on the spectrum," notes parent Cory Gilden, "demands a lot of time and energy. Fortunately, a system of respite enables caregivers to take a break."

Defined, *respite* is the temporary care of an individual on the spectrum, which gives the primary caregiver a short interval of relief. In Delaware, respite care—or reimbursement for respite care—is available in a number of ways:

Delaware Autism Program

Is your child enrolled in the Delaware Autism Program (DAP) through the Christina, Brandywine, Caesar Rodney, Capital, Seaford, or Cape Henlopen School District?

If so, your child is eligible to receive respite care at a discounted rate. This rate is based on a sliding scale according to your child's qualification for a free or reduced-cost lunch. For example, if your child pays full price for lunch at Brennen School, the DAP-provided respite currently costs \$3.81 per hour. For students who get reduced-cost lunches, respite costs \$2.28 per hour; free lunches, \$0.76 per hour.

Each school has its own process for connecting you with the respite coordinator, so call your DAP school to begin. Be sure to note the specific dates and times you want the respite for your child.

For each student, respite is limited to 24 hours per month. This allotment expires at the end of each month, but an additional seven days are also available throughout the year.

Your request will be sent to DAP-employed professionals and paraprofessionals in the respite program to see who's available. If you would rather

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Speak personally to a potential provider (such as your child's teacher, for example), you still need to contact the respite coordinator to make proper arrangements.

Delaware Lifespan Respite Care Network

The Delaware Lifespan Respite Care Network helps you connect with respite care providers. Call (302) 324-4444, and speak with someone personally. Or visit delrespice.com, and type in your criteria.

You will choose from a list of providers who offer respite at different locations, times, and prices. You may also name your own provider, such as a family member. Be sure to apply well before the respite care is needed.

The network offers financial assistance in the form of a scholarship. The scholarship recipient may receive about \$500 in a calendar year. This amount can be less if a large demand is made on respite services.

Nursing agencies

If an individual on the spectrum needs daily medical attention, nursing agencies provide short-term care but often have small staffs in high demand. Your name may be added to a waiting list. Be sure to apply well in advance of when the care is needed.

To find an agency that meets your needs, check the Delaware Lifespan Respite Care Network. Or directly contact an agency, such as Nurses 'n Kids, Bayada Home Health Care, Maxim Healthcare Services, or Interim HealthCare of Delaware.

Some Medicaid waivers may cover the cost of a nursing agency. To see if you qualify, call Delaware Family Voices at (302) 221-5360. Ask for the director, Ann Phillips.

Division of Developmental Disabilities Services

The Delaware Health and Social Services' Division of Developmental Disabilities Services (DDDS) reimburses the cost of respite care for anyone but the primary caregiver. But to receive reimbursement, you must be registered with DDDS. The process (which is similar to registering with Medicaid) involves a case worker and the completion of a large packet of information. Once you are registered, you can submit a request for respite reimbursement.

The rate of \$10 per hour can be used to pay for a respite provider or for a program, such as summer camp. To receive this reimbursement, email the DDDS coordinator each month; list the specific dates and times the respite provider was needed. DDDS will then send a check for that month's respite care.

For more information about DDDS respite services, call Bonnie Hummer at (302) 933-3145. Or visit dhss.delaware.gov/dhss/ddds.

Getting more out of respite care

Some respite funding can be used for more than the cost of care; it can also cover camp fees for children on the spectrum. "I know several families who used some of their children's yearly respite funding from DDDS to cover the fee for the Autism Delaware Summer Day Camp," notes the camp's coordinator, Autism Delaware Southern Service Coordinator Dafne Carnright, MS, LPCMH. "And some families used funding found through the Delaware Lifespan Respite Care Network.

"If you want to pay camp fees with respite funding, be sure to tell the agency when you apply," advises Dafne.

"I have also talked to families who don't use respite care for a variety of reasons, but I recommend that families investigate respite options early in their journeys," adds Dafne, who's also the mother of a child on the spectrum. "It's important for both parents and children to have time away from each other. Rested and recharged, you take better care of your loved ones—and your child learns how to function without you. I mean, consider this: What if you have an emergency and your child needs to spend time away from you—and never has before! Imagine your child's reaction.

"I suggest you try some time off just once," continues Dafne. "For your own peace of mind when hiring respite care, ask about the training and experience of the providers, and follow your instincts. Start with one or two hours of respite. Maybe go grocery shopping by yourself. Before you know it, your child will be enjoying new, positive experiences, and you will be enjoying much-needed breaks."



Helping People and Families Affected by Autism

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(302) 644-3410

Considering summer camp

Are you thinking about sending your child or sibling with autism spectrum disorder to summer camp? Here are some considerations for getting the best fit for you and the child.

Ask for recommendations. Start with the child's teachers or specialists. After all, they have gotten to know the child and may have an idea for reinforcing a piece of the individualized education program (IEP) over the summer.

When you have the names of some recreational or camp sites, contact the program coordinators. Here are some questions to ask:

Is the camp considered residential, specialty, inclusive, or a day camp? Does it offer indoor or outdoor activities that the child is interested in?

Can the child play sports or interact with animals? Can the child choose what to take part in? And is adapted equipment available if needed?

Does the child have a personal quirk? If the child needs to wear socks in the pool, for example, be sure to tell the counselors to avoid a poolside meltdown.

Is the camp accredited with the American Camp Association (ACA)? An ACA-accredited camp is set up according to specific standards concerning operation, program quality, health, and safety. For details, visit acacamps.org.

Is the campus accessible to the child's physical needs? Unless the camp has a religious affiliation, it must satisfy accessibility standards set by the Americans with Disabilities Act (ADA). But if your child needs paved pathways to navigate safely and the camp has only gravel or dirt trails, then this camp is not a good fit.

If the child wants to go away to camp, overnight accommodations need to be considered. These can

range from tents and tepees to cabins. Can the child even tolerate an overnight stay with new tent mates? Are the accommodations air-conditioned? Do they provide quiet space for down time? And are the accommodations staffed at night?

Also consider the size of the group the child will be joining. A child who is accustomed to only four people in a classroom needs to be acclimated before joining a camp with 30 children.

The people taking care of the child need to be considered, too. Who are they? How thorough is the staff application process? What is the minimum age requirement? What qualifications are required? Does the camp perform background checks on all staff? And how will the child's personal information be shared with staff?

Is the staff required to complete any training relative to the camp? Important certifications include life-guarding, CPR and First Aid, and emergency management.

Also, is the staff trained in disability awareness and camper care? Staff needs to be able to address all of a child's special needs.

What is the staff-to-camper ratio? If the child needs constant one-on-one supervision but the staff-to-camper ratio meets the need for only minimal assistance (1:3), then this camp is not a good fit.

What type of medical support is available? The ACA recommends an on-site licensed physician or registered nurse. In case of injury or illness, will you be notified?

In addition to physical safety, the child's emotional and social safety should be considered. How will the child's behavioral plan be addressed? How is undesirable behavior defined and addressed? Does the camp have a clear definition of acceptable behavior?

The above considerations were gleaned from *Discover Camp*, a publication of The National Center on Physical Activity and Disability, copyright 2010, Board of Trustees of the University of Illinois.



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