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Parents of special-needs kids face challenges finding baby sitters

It's challenging for many parents to find a good baby sitter, but it can be even more difficult for families with special-needs kids.

"It's a real issue, especially when kids have pretty intensive needs," said Jodi Reimer, coordinator for the Arc of King County, Wash.'s Parent to Parent program. "You have to get real creative sometimes."

Baby sitters may be reluctant to change a 6-year-old's diapers or take responsibility for children with medical needs. "People get leery -- what if something happened?" Reimer said. Additionally, many teenagers with developmental or physical disabilities need supervision but balk at being "baby-sat."

Parents say they rely on relatives, siblings, neighbors, friends, school aides or college students specializing in special education or physical therapy to grab time for much-needed dates or time without kids. "Or what happens is parents just don't go out much, or one goes and one stays," said Reimer, whose son, Kellen, 14, has Down syndrome. "Caregivers face a lot of burnout."

When parents use Sittercity.com to find occasional care for special-needs kids, the most common queries are for autism, Down syndrome, epilepsy and attention-deficit disorder, said Genevieve Thiers, CEO of the baby sitter matching service.

In Seattle, only 22 of the site's 1,041 registered local sitters say they specialize with special-needs children, she said. The fee-based site is starting a pilot program in New Jersey to recruit more sitters to work with special-needs kids.

"When we get calls from parents for this, they're really desperate," Thiers said.

Several parents cited the benefits of respite care from the state Division of Developmental Disabilities (DDD), but that's no longer a viable resource. Part of the Department of Social and Health Services, the division offers a \$1,400 yearly allocation for respite care and other services.

But with a waiting list of 8,530 eligible clients, the line "isn't moving very fast," said DDD communications manager Shaw Seaman. Funding for the program, which currently serves 2,672 clients, hasn't been upped since the 2000-2001 fiscal year.

While Seaman says it's "a neat program and good for families," DSHS' ongoing financial crunch forced difficult decisions, and "family support respite just hasn't made it through the final cut."

Many sitters worry special skills are required, but that's often not true, said Adrienne Fatur, a resource specialist for Child Care Resources. "People hear a label and then are afraid they're not qualified," she said. "But once they meet the family and child, it really turns out that the skills they already use with children are the same ones they need now. Getting over that fear is the big step."

Most special-needs children do require greater supervision and involvement from the sitter, Reimer said. "It can't be someone who just comes over to do their homework and watch TV," she said. She's found the best sitters often have siblings with special needs so "it's no big deal."

The Glas family was fortunate to have a teenager in their Ravenna, Wash., neighborhood who went through Camp Fire's Special Sitters program and watches Erika, 7, and Paul, 4, who has Down syndrome.

So far, finding baby sitters hasn't been difficult since Paul is young and doesn't have any medical issues, said mom Linda Glas. They've also hired aides from his preschool, the Experimental Education Unit at the University of Washington, and signed him up for activities through Seattle Parks and Recreation. With new sitters, she explains what certain sounds mean so they understand his limited speech.

It's harder for parents of special-needs teens, who have to balance teens' need for care with their demands for independence.

Teens with developmental disabilities "may be more like dealing with younger children, but with the physical capability of teenagers," Reimer said. For example, they can unbuckle themselves from the car and be out in the parking lot before a caregiver expects it.

Lou-Jean Buxton of Seattle worked with Highline Community College's Respite Care Program to find a student who could take her son Taylor, 17, on outings. Though Taylor is "very capable and able," speech challenges and wheelchair use because of spina bifida leave him more vulnerable and socially isolated.

"Because he's verbally challenged, people assume it's a mental thing, but it's not," Buxton said. "I often tell people, 'He understands everything you say; he's just not going to get it back out.'"

Using a converted van, the college student accompanied Taylor when he volunteered at the library, visited an art museum and hung out at the mall. "It was really nice as a parent that I could get something done but know he was out doing something fun," Buxton said.

When Taylor was younger, Buxton relied on a neighbor who was a licensed respite care provider, as well as her older son, who is five years older than his brother.

"It was hard when we went to the college since that was outside our neighborhood and outside what I knew and trusted," she said. "But it worked out well."

Letting go and trusting other caregivers can sometimes be the hardest part for parents, who often feel especially responsible for children with special needs.

"We're used to his intense needs," explained Reimer. "To try to hand that over to someone who's not used to it is kind of scary."

"The whole time, I'm thinking, 'Is the sitter able to understand him? Is he safe? Is he getting his needs met?'" she said. "It's hard to turn that off and just relax."

PARENTS SHARE TIPS

Ask child care center staff or school aides if they would baby-sit for extra money. Call or post notices at local community colleges or universities for child development, special education or physical or speech therapy students.

Network and trade sitting with other parents of special-needs children. "Other parents of children with special needs are used to the level of supervision necessary," explained Jodi Reimer of coordinator of Arc of King County, Wash.'s Parent to Parent program. "They don't get all nervous about a child with special needs coming over and their house is usually set up for it."

Start early. It's easier to find sitters when children are younger. Once a relationship is established, a sitter is more likely to be comfortable working with an older child.

Expect to pay more. Especially for sitters with specialized training.

Buy season tickets. Or find something else that will force you to set up a regular sitter and make time to get a break.

Be sure to check references.