

Funding shrinking for the growing special needs population

By Michelle Cottle, Newsweek

What could really save Hillary Toucey's life is a personal-care attendant to help with her 7-year-old son, Eli. Dark-haired, fair-skinned, and fragile, Eli suffers from a raft of health problems: cerebral palsy, celiac disease, epilepsy, asthma, and what his mom calls "pretty severe" autism.

His speech is "kind of garbled"; he has leg braces and a wheelchair; seizures render him incontinent at night; and he has acute sensory sensitivities. He cannot bear to touch Styrofoam or the paper wrappings on crayons. Loud music sends him into a panic. When his first-grade class took a field trip this Christmas to see *The Cajun Nutcracker*, "we lasted three minutes," says Toucey.

Eli is extremely attached to his mother. Toucey spends as much time with him as possible, but since her divorce, the 32-year-old Louisianan has been attending nursing school in the hopes of escaping her hand-to-mouth existence. When her husband left in November 2009 (two weeks before their 10th anniversary and four days after Toucey had surgery for a thyroid tumor), he took the car with him. Toucey isn't sure when she'll be able to afford another one.

Eli's seizures and social issues make it all but impossible to leave him with a random babysitter. "There's only a handful of people he can be with," says Toucey. Having one of the state's personal-care attendants (PCAs) come in for 30 hours a week would make a world of difference: the attendant could take him to therapy, help him practice life skills like brushing his teeth and showering, watch him while Toucey studied. Maybe

then she could give more attention to her other kids: 11-year-old Jonah, himself diagnosed with Asperger's, who cries easily and doesn't have many friends; and Charlotte, "a perfectly healthy, wonderful, brilliant" 9-year-old who her mom fears will fall through the cracks. "I feel horrible," says Toucey. "I really have to carve out time for her." Toucey has been told that the PCA bureaucracy can take "forever," and she calls the agency constantly to make sure the process hasn't stalled. Taking care of the essentials is pretty much all she can handle these days. Says Toucey matter-of-factly, "I have no life."

Now and again, the spotlight falls on the challenges of raising special-needs children. In 2008 Sarah Palin captured public attention with her son Trig, who has Down syndrome. This election cycle, Rick Santorum did so with heartbreaking stories about 3-year-old Bella, who suffers from Trisomy 18. Dramatic parenting moments often take the spotlight: stories of diagnosis, acute health crises, surprise breakthroughs.

But for most parents, it's the day-to-day stuff that consumes them: the hours of therapy, the doctor visits, the financial pressures, and the grinding anxiety that comes with it all. It is a rough, often isolating road. And one that promises to become even more challenging as our society enters a new, more complicated era of caregiving. That era is coming in part because many of the medical and social advances that have improved the lives of special-needs individuals have also increased the burden of caring for them. For instance, people with Down syndrome were once lucky to survive to age 30; today, the average lifespan is 55. This presents parents (and society more broadly) with the challenge of somehow providing for an adult child decades after their own deaths, a situation complicated by the fact that the Down population develops Alzheimer's at a rate of 100 percent, typically in their 40s or 50s.

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