

## The extra layer of back-to-school anxiety when your child has special needs

This is an especially hard time of year for all parents of children with special needs. We are cutting tags out of clothes, filling out forms, buying special shoes, negotiating bus routes and trying to determine the gaps in services for our children. That is not to diminish the anxiety of parents of typical children. Many parents worry about the first days of a new school year, about cyber bullying and peer pressure, about racial inequality and adequate resources in public schools, about whether their child will fit in. It is fun to laugh about our freedom as parents on the first day of school, and it may be a well-earned laugh after a summer of squabbling and cries of boredom, but it is often a privileged laugh.

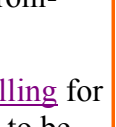
In the summer, my son does not have to fit a mold, and as a result, he flourishes. A few weeks ago he swam in Lake Michigan for the first time, and I saw my little boy so strong and independent. I want him to remember facing that open water and diving fearlessly under the current to swim when he gets overwhelmed at school.

Under the U.S. [Individuals with Disabilities Education Act](#), students with disabilities are provided with a free public education that is tailored to their individual needs. The specific accommodations are spelled out in a legal document called the [Individualized Education Program](#). It is a right but not a given. It can be a battle to get our children the support they need and deserve, and many parents of kids with special needs approach the school year knowing this.

Zoubida Pasha, a bilingual parent advocate for the Family Resource Center on Disabilities in Chicago, said parents should reread their child's IEP before the start of the school year to become familiar with it again. The IEP must be in place on the first day of instruction. That means teachers cannot legally tell parents they need a grace period to observe the child or make their own assessment before providing the accommodations stipulated, Pasha said.

She also advised parents to help teachers learn about their children outside of the IEP, which typically includes a description of the child by former teachers, therapists and evaluators. Pasha does this for her daughter, who is in high school. "Feed them what was done during the summer, what skills that they have learned or upgraded or dropped," she said. "Make it big accomplishments, an achievement, I don't care what it is. Make sure there is that solid communication."

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## Deadline for Electronic Check-in for Home Care Workers Pushed Back

Congress has passed and President Trump has signed a law delaying by one year the requirement that providers of home health care services clock in electronically with Medicaid prior to performing services.

[Disability rights advocates and a bipartisan group of senators had been calling](#) for the state-by-state rollout of Electronic Visit Verification (EVV) programs to be delayed. Congress enacted the requirement in 2016, as part of the [21st Century Cures Act](#), as a way to prevent caregivers from billing Medicaid for fraudulent home visits. The law obligated each state to develop its own EVV system by 2019. The new law delays that until 2020.

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## Senate Bill Would Set Up Federal Office of Disability Policy

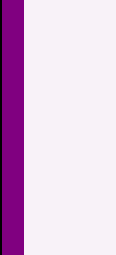
Each year, hundreds of bills and regulations are proposed with little if any analysis of how they will affect the lives of people with disabilities.

If signed into law, a new Senate bill, titled the [Office of Disability Policy Act of 2018](#), would change this. Introduced July 24, the legislation would create an Office of Disability Policy within the nonpartisan [Government Accountability Office \(GAO\)](#) to analyze the impact of proposed federal legislation, regulations and guidance documents on individuals with disabilities.

"Too many policy makers fail to consider how their bill or proposed regulation will affect Americans with disabilities and their family members," the Office of Sen. Bob Casey (D-PA), the bill's leading sponsor, wrote in an [advocacy document in support of the bill](#). "Individuals with disabilities, their family members, service providers and advocates deserve to understand the positive or negative affects executive actions or legislation will have on their lives."

Among its tasks, the Office would be required to gather data and analysis on proposed and existing legislation, regulations and guidance documents, and analyze their compliance with federal disability rights laws, such as the Americans with Disabilities Act and the Individuals with Disabilities Education Act.

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## Update on Medicare Home Health Coverage

*Your Medical Condition Does Not Have to Improve to Qualify for Medicare Coverage*

An important federal case called Jimmo v. Sebelius, set new standards where Medicare beneficiaries who receive skilled nursing and/or skilled therapy **can** qualify for Medicare extended coverage for homecare services when:

1. The person is either homebound or can go out, but the person needs the assistance of another or of a supportive device to travel outside the home.
2. A physician orders and certifies that the skilled care is needed.
3. A physician or other health care professional has a face-to-face meeting with the individual prior to certifying the individual's need for home health care.
4. A document about the face-to-face meeting, signed by a physician, is included in the home health care certification.
5. The individual requires skilled nursing care on an occasional basis, or skilled physical therapy, speech-language pathology services or occupational therapy, only on a short term or occasional bases (to continue care once Medicare coverage has begun).
6. The care is provided by Medicare-certified home health agency.
7. If the above requirements are met, Medicare will also cover skilled care, as well as the necessary and reasonable in-home health aide services, social services, and some medical supplies.

**Please note:** Skilled care is not just physical therapy, it can be skilled nursing services such as wound care or testing. Occupational and speech therapy are also skilled services.

**Remember:** Medicare home health coverage is not just a short-term, critical care benefit. Under the Jimmo case, Medicare beneficiaries who qualify are eligible for home health coverage, when skilled care is reasonable and necessary, not only for rehabilitation, but also for maintenance and to prevent deterioration.

For more information, please visit:  
[Center for Medicare Advocacy/Jimmo v. Sebelius](#)

## The Mental Health Apocalypse Starts Now

-Gaps in our mental health system spell doom

The American mental health system needs vast reform, not because of mass murders, which attract most of the attention but have much less to do with mental illness than commonly believed. The mental health system needs improvement because:

- 60% of people with diagnosable mental disorders do not get treatment.
- In most parts of the U.S., the capacity to treat people with mental illness is simply inadequate.
- Access to available care is often limited by cost, distance, office hours, stigma, etc.
- Of those who get treatment, at most 1 in 3 get even minimally adequate treatment.
- The mental health service system is fragmented, with inadequate coordination among mental health providers, between mental health and substance abuse providers, between behavioral and physical health providers, and with other human service providers.
- People with serious mental illness die 10-25 years younger than the general population.

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## Tax reform affects ABLÉ accounts, saver's credit, 529 rollovers

IRS Tax Reform Tax Tip 2018-136, August 30, 2018

The Tax Cuts and Jobs Act made several changes to [ABLE accounts](#). ABLE accounts were created by The Achieving a Better Life Experience Act of 2014. They are authorized tax-advantaged section 529A accounts to help disabled people pay for qualified disability-related expenses.

[Click Here to read how the changes will affect the annual contribution limit, saver's credits, rollovers, and transfers from section 529 plans](#)

[MiABLE Update Fall 2018 — Michigan Department of Treasury](#)

## Can a Special Needs Trust Pay for Housing Without Reducing SSI Benefits?

Trustees of special needs trusts [generally have wide discretion](#) in determining whether to distribute funds to trust beneficiaries. But if the person with disabilities receives [Supplemental Security Income \(SSI\)](#), careful precautions should be taken before any trust funds are used to pay for housing costs.

The most critical factor in determining whether SSI recipients are eligible for the maximum benefit [is their housing arrangement](#).

People living alone who pay their full rental expenses, including utilities, are eligible for the maximum monthly SSI benefit, assuming they would otherwise be eligible for the maximum. Likewise, where the SSI recipient lives with another person or persons but pays their proportionate share of the rent, the recipient is eligible for the maximum SSI benefit.

However, where a third party pays the rent—be it a parent or a special needs trust—the Social Security Administration (SSA) [will cut the maximum federal SSI benefit by one-third](#), plus \$20.

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## Say a Little Prayer: Aretha Franklin Had No Will, and a Child With Special Needs

According to court documents, legendary singer Aretha Franklin did not have a will when she died, despite reportedly having a son with special needs. The lack of a will opens up the intensely private singer's estate to public scrutiny and unnecessary costs, and means that there are no specific provisions to protect her son.

When someone dies without a will – called dying "intestate" -- the estate is divided according to state law. Under Michigan law, an unmarried decedent's estate is distributed to his or her children.

Even if the "Queen of Soul" had wanted her estate to go solely to her children, by not having a will or trust, her estate will have to go through a long public probate process, which will likely cost her estate considerable money. If Franklin had created an estate plan that included a will and a trust, she could have avoided probate and kept the details of her financial circumstances private.

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