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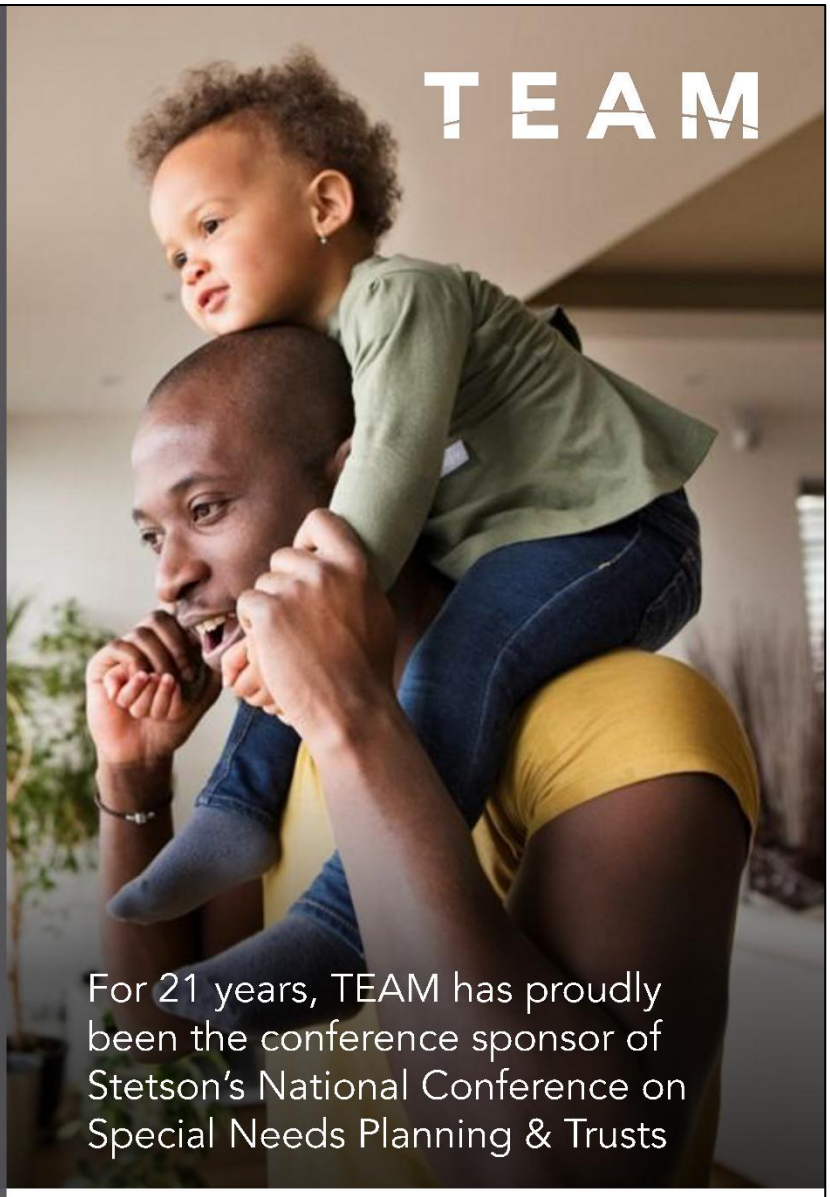
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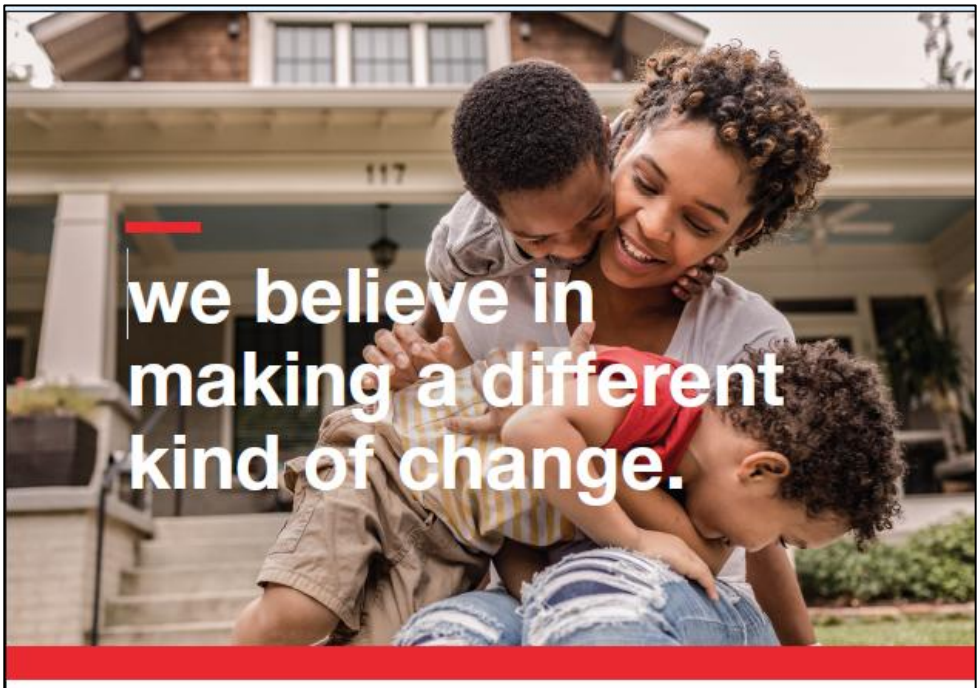
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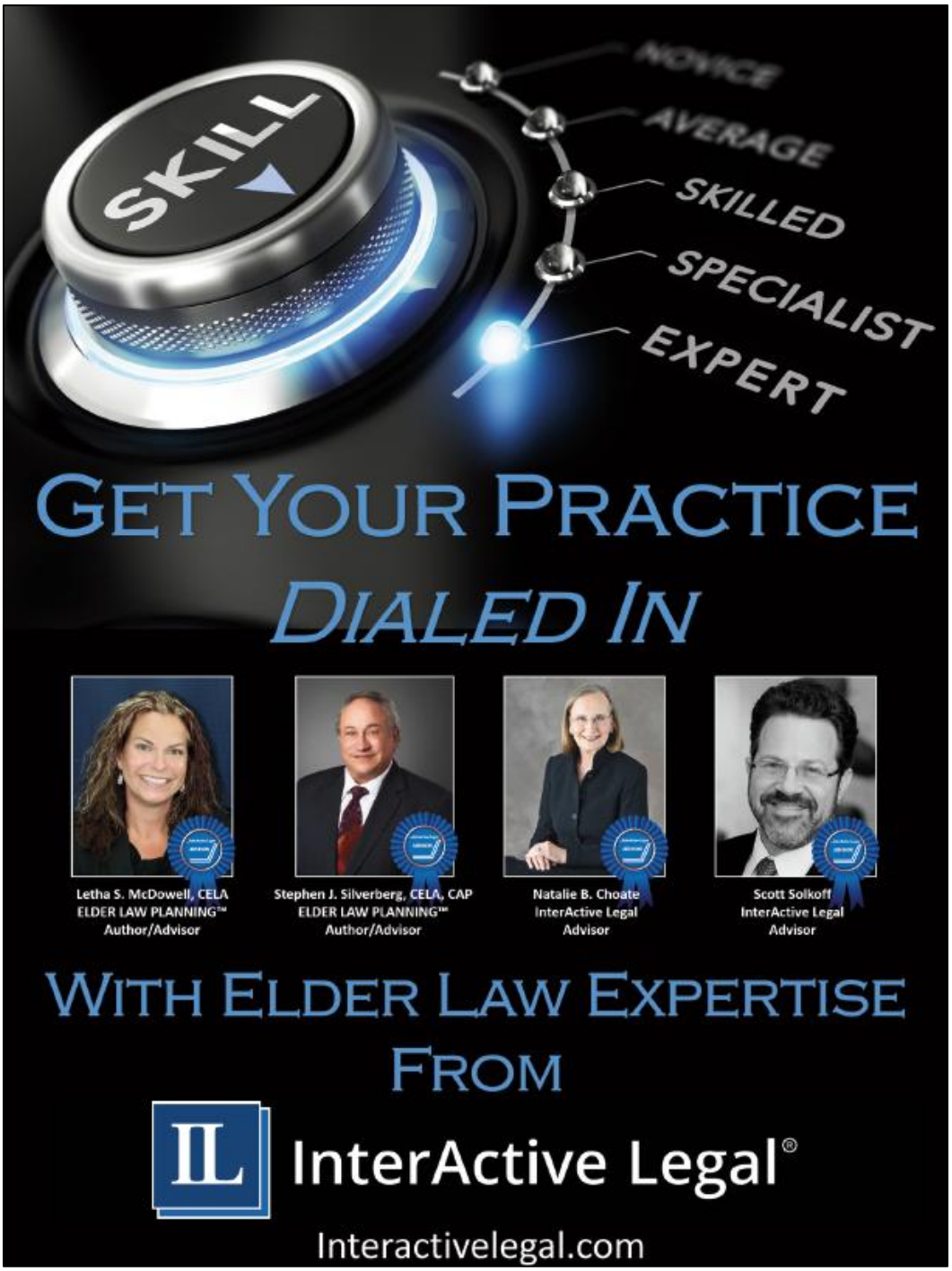
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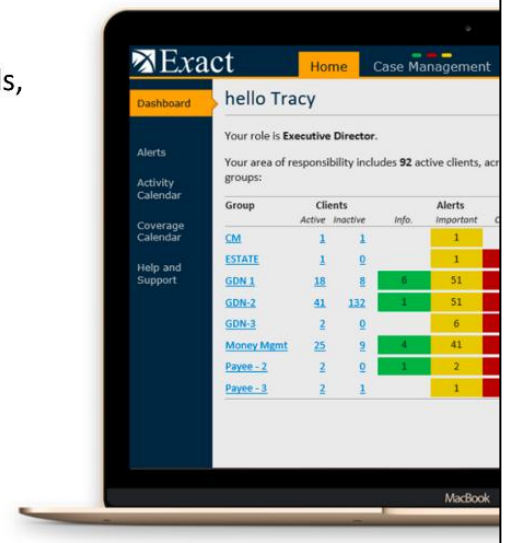
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How Media Cover Stories of People with Disabilities

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NCDJ and disability reporting

Jennifer LaFleur
UC Berkeley School of Journalism

A place for journalists to better their craft

Written by former Cronkite School student Annie Woods

As a freelance photographer in San Francisco, Suzanne Levine specialized in disability issues, and what she saw in the news bothered her.

She felt that people with disabilities were often caricaturized and that news about disabilities was often inaccurate or incomplete. She decided to take things into her own hands, buying a book on how to start a nonprofit organization, getting a team of journalists and people with disabilities together, and founding the Disability and Media Project.

For more than 10 years, Levine helped lead presentations for journalists and journalism educators and developed materials to help journalists do their jobs better.

As she moved across the country, the center moved with her, from San Francisco to Boston. Along the way, its name was changed to the National Center on Disability and Journalism to better reflect the organization's focus on journalism as opposed to advocacy.

In 2008, the center found a new and permanent home at ASU's Walter Cronkite School of Journalism and Mass Communication.

"I felt that the school already had a strong commitment to diversity and it had the best chance of succeeding and growing the program," Levine said. "People haven't been exposed to disability issues, and I think they're most receptive when they're in school."

Kristin Gilger, NCDJ's founding manager and former executive director, said the center's aim is to provide practical resources to help journalists better report on disabilities and people with disabilities.

"We want reporters, for example, to come to the center when they have questions on how to describe a disability or where to find a particular resource," she said. "Sometimes, they might just want to see what other reporters are doing or share what they're doing that advances the depth and quality of coverage in this important area.

"This isn't an advocacy group," Gilger said. "It's a place for journalists to better their craft."

Since that time, NCDJ has worked to increase meaningful disability reporting through training, tip sheets, an annual journalism contest and its language style guide. (cronkite.asu.edu/ncdj/disability-language-style-guide)

More than 25% of the U.S. population has a disability, but ableism —stereotypes and harmful narratives about disability — are still rampant. Most coverage of people with disabilities has been stereotypes without coverage of actual policy.

NCDJ has worked to train newsrooms to do stories on a variety of beats that can have impact:

- Public policy
- Environment
- Education
- Transportation
- Housing
- Health care

Disability reporting

Julia Métraux of Mother Jones has reported extensively on systemic issues affecting people with disabilities. (www.motherjones.com/author/julia-metraux)

Amy Silverman of KJXX in Phoenix has done reporting for a variety of outlets related to services for people with developmental disabilities. (www.amy-silverman.com). She also does training in the use of plain language for news outlets.

Joseph Shapiro of NPR has covered disability issues for many years. (www.npr.org/people/2101159/joseph-shapiro)

The nonprofit newsroom **ProPublica** (www.propublica.org) has published reporting on disabilities and education as well as how changes in federal policy are impacting people with disabilities.

Before it closed its investigative arm **BuzzFeed** reporters investigated private equity ownership of homes for people with disabilities. (www.buzzfeed.com/uk/tag/private-equity)

For more examples of disability reporting across the U.S. and internationally, check out NCDJ's contest archives. (cronkite.asu.edu/ncdj/annual-contest) and disability and journalism expert **Beth Haller**'s blog (media-dis-n-dat.blogspot.com)

Jennifer LaFleur has reported on states' failures to comply with the Supreme Court's Olmstead Decision. Her reporting on transit in metropolitan St. Louis led a federal investigation of the agency.

Common media tropes

- People with disabilities can't speak for themselves.
- Disability is a weakness.
- Disability is a super power.
- Disability is something people want to or need to overcome.
- Accessibility and accommodations are special favors or need to be earned.
- Facilities/programs/websites don't have to be accessible.
- The views/positions of the disability community are the same.

Language choices

- Refer to the disability only when it's relevant to the story.
- Use accurate language, referring to a specific diagnosis when possible.
- Use neutral language, avoiding implications that disability is inherently bad
- If it is relevant to the story, ask the person how they would like their disability to be characterized.
- Remember that the needs for accommodations are not special treatments or favors.
- Person-first language puts the person before their disability
- Identity-first language puts the disability at the center
- If you're not sure what language to use, ask.

Datasets to mine

- Disability benefits data for adults and children receiving (from the Social Security Administration)
- Workforce training funding for people with disabilities from the U.S. Department of Labor
- Elections data and voting access for people with disabilities
- Microsoft, World Bank and Fordham University are creating a disability data hub.
- U.S. Department of Education, Office for Civil Rights - (ocrdata.ed.gov/ (Get it while it lasts.)
- U.S. Census data - www.census.gov/topics/health/disability.html
- Understanding the law and breadcrumbs to lead you to the best data

Additional resources and references

- NCDJ Style guide (included in materials, but also at cronkite.asu.edu/ncdj/disability-language-style-guide
- IRE Reporting on Disability (included in materials, but also at www.ire.org/2025/02/10/reporting-on-inequality
- GIJN guide to reporting on disabilities. (gijn.org/resource/disabilities-guide-short-version)
- "Supporting Journalists with Disabilities" from Investigative Reporters and Editors (www.ire.org/2024/12/16/ire-radio-supporting-journalists-with-disabilities/)
- Disabled Journalists Association (discojourno.com)
- Covering disabilities from the Poynter Institute (www.poynter.org/reporting-editing/2005/covering-disabilities-untold-stories-for-any-beat)
- State Centers for Independent Living (acl.gov/programs/aging-and-disability-networks/centers-independent-living)

Reporting on inequality

By Jennifer LaFleur, UC Berkeley Graduate School of Journalism

Imagine a broad group of people regularly excluded from social, governmental and employment activities because systemic and structural barriers keep them out.

A pretty important story, right? Yet it's one that too often goes uncovered.

For investigative reporters, it's an opportunity to do data-driven stories that can have real impact. No matter what your beat is, you will find disability stories.

Years ago, a colleague and I were reporting about disability issues in St. Louis. People with disabilities told us again and again that the biggest problem they faced was inaccessible transportation. Buses were often not accessible to blind riders or riders who used wheelchairs and it was nearly impossible to schedule a trip on the door-to-door paratransit service. To lay the groundwork, we had to do a lot of homework to understand how transit systems are supposed to serve disabled riders. We also had to compile some of our own data because what we needed didn't exist. The series resulted in a federal investigation of the transit system and improved service for disabled riders.

To start, understand how systems are supposed to function so you can identify what's not working. That process likely will lead you to the documents and data that can help you uncover the story.

This past summer, a team at The Washington Post investigated programs for workers with intellectual and developmental disabilities. They start at subminimum wages but are supposed to move into higher paying jobs. But many never do. An analysis of Labor Department records found that "at least 38 percent of current employers in the program have violated compensation and other rules and cheated disabled workers out of millions in pay."

In 2022, the Houston Chronicle reported that nearly 200,000 Texans with disabilities were waiting for services from the state through its Medicaid waiver program. Some families waited for years.

These are not isolated patterns. They are happening across the country and likely will worsen under President-elect Donald Trump's proposed policies.

In June, NPR's Joseph Shapiro investigated the Supplemental Security Income program, which keeps many disabled people from marrying because they risk losing benefits. "Many disabled people get caught by this 'marriage penalty,' a left-over rule from decades ago when government policies didn't account for disabled people finding love and getting married," Shapiro wrote.
In the Center for Public Integrity's "Institution of One" series, Amy Silverman found that "despite strides in community-based services for people with disabilities, staff shortages and lack of training mean that individuals aren't getting the services they need."

Know the laws

Disability rights are protected by federal laws, as well as some state and local laws.

The Americans with Disabilities Act covers different types of entities.

- Title I — Employers with 15 or more employees must provide equal access to employment. Complaints are filed with the Equal Employment Opportunity Commission.
- Title II — State and local governments must provide equal access to their programs. Complaints may be filed with local ADA coordinators or with the U.S. Department of Justice and other federal agencies.
- Title III — Businesses and nonprofits must comply with basic requirements that prohibit exclusion, segregation and unequal treatment. Complaints are filed with the U.S. Department of Justice.
- Title IV — Telephone and television services must be accessible to people with hearing and speech disabilities.

Government and other public websites also must be accessible. In 2021, the DOJ reached a settlement agreement with Rite Aid Corporation because the company's COVID-19 vaccine booking website was not accessible to some people with disabilities. (Keep this in mind for your own website — especially when reporting on disabilities.)

The Fair Housing Act prohibits housing discrimination and requires owners to make reasonable accommodations. Complaints are filed with the U.S. Department of Housing and Urban Development.

The Air Carrier Access Act requires commercial air carriers to provide boarding assistance and certain other accessibility features in new aircraft and airport facilities. Complaints are filed with the U.S. Department of Transportation.

The Mental Health Equity and Substance Abuse Parity Act requires that certain insurance providers cover mental health benefits on par with medical benefits.

Disability data

Data can drive many of these stories to reveal the full extent of problems. If something is enforced, licensed or funded, there likely is a database.

But don't stop there. Talk to disabled people and disability rights organizations to learn about their experiences, said Beth Haller, a longtime media and disability researcher and author of "Disabled People Transforming Media Culture for a More Inclusive World."

Below are a few places to look for disability data on a variety of beats.

Jamie Muniz organizes hangers at Pathways to Independence in Kearny, New Jersey. Washington Post reporters Amanda Morris, Caitlin Gilbert and Jacqueline Alemany featured his experiences in their investigation, "Some Disabled Workers in the U.S. Make Pennies per Hour. It's legal." JACKIE MOLLOY / THE WASHINGTON POST

Census

The U.S. Census Bureau's American Community Survey asks six questions about whether a respondent has difficulty with certain activities. In 2023, the Census Bureau proposed a change that would have decreased the proportion of people who would be considered disabled. As a result, funding for programs that serve people with disabilities would have been reduced. In February, the Census Bureau announced that it would not change the questions.

Education

The Civil Rights Data Collection from the U.S. Department of Education tracks access to programs, presence of police, use of restraints and other factors and reports them by race and ethnicity, disability status and English learners. Use this data with caution and double-check any findings with local school districts.

State departments of education and school districts also track participation in what are referred to as "special education" programs.

Parents often struggle with getting the services that allow their children to participate in school. They can help you understand what barriers they face. The Idea Center works with states to improve data collection and analysis.

Employment

The unemployment rate for people with disabilities is double that of workers without disabilities, according to the latest data from the U.S. Department of Labor. Disabled workers often are underemployed because they risk losing benefits if they earn too much money. State departments of labor also track data that might be helpful.

Environment

As sea levels rise and weather events become more extreme, the impact is higher on people with disabilities living in those areas. “Research shows people with disabilities are up to four times more likely to die in disasters than the general population. And, according to U.S. census data,” Judy Woodruff reported in 2023 for PBS, “most people with disabilities never return to their homes after a disaster.”

Evacuating when you have a disability can be more difficult and emergency plans may not include procedures for people with disabilities. In addition, compromised health may make people more vulnerable to extreme heat or exposure to pollutants.

Health care

Shortages of medical providers at all levels make it hard for people with disabilities to find care. The Health Resources & Services Administration tracks data on the healthcare workforce.

The lack of accessible medical offices has long been an issue for disabled patients, but a new rule will require medical facilities to be more accessible.



Zainab Edwards takes skating lessons at the Ice Den in Chandler, Arizona. Her story was featured in Amy Silverman's 2022 article, "Million-Dollar Question: How to Find Safe Homes for Those with Complex Needs," for The Center for Public Integrity. RICK D'ELIA / PUBLIC INTEGRITY

Housing

Many people with disabilities continue to live in institutions because they cannot find affordable accessible housing. Many communities have a shortage of affordable housing, but the problem is even worse for those who need accessible housing.

The U.S. Department of Housing and Urban Development publishes several housing data sets. Your local housing authority also should have data on housing.

Politics

Disabled voters can face a range of barriers to casting their ballots from inaccessible polling places to limits on options such as vote-by-mail. According to a study conducted for the U.S. Commission on Election Assistance, "about one in seven voters with disabilities encountered difficulties voting in 2022."

While some states have added options, such as vote-by-mail that make voting easier, many new voting laws make it harder for people to cast a ballot.

On Nov. 3, MSNBC columnist Eric Garcia wrote about the issue of polling places in churches, which are exempt from the ADA. "About 20% of polling places are in churches," he wrote. That number is much higher in some states.

Local boards of election typically have data about polling accessibility, but it's worth ground-truthing that data. In St. Louis, we found that a significant number of polling places coded as accessible by the elections board were not.

Transportation

Lawsuits and complaints are a good place to find disability stories on the transportation beat. The DOJ publishes cases on its website.

In 2020, for example, the DOJ reached a settlement agreement with Amtrak requiring the agency to make stations accessible and pay $2.25 million to victims affected by its inaccessible stations.

Data about public transportation is available from the Federal Transit Administration, which tracks things such as the number of accessible vehicles an agency has. It also does triennial reviews of transit agencies.

Transit agencies track everything from vehicle repairs to bus stops, which gives local reporters plenty of opportunities to dig into data.

Air travel is another place where people face barriers. News outlets have reported how frequently wheelchairs are damaged by airlines.

“People don’t realize that this is a part of my body. If this is broken, you’ve broken my legs,” Illinois Sen. Tammy Duckworth told NPR earlier this year. “Imagine if the American public saw that the airlines broke 892 pairs of legs in a single month. There would be hue and cry, but there hasn’t been.”



Chase Brown, a 29-year-old with autism, sits in his bedroom in his home south of Spring Branch. Chase is one of about 170,000 Texans waiting to receive intellectual and developmental disability services through one of six Medicaid waiver programs, which use state and federal funds to get people care in the community instead of in an institution. MARK MULLIGAN / HOUSTON CHRONICLE

International resources

Accessibility outside the U.S. varies widely as does the availability of data.

Arab Reporters for Investigative Journalism conducted a survey that found that in Amman, Jordan, “the city’s buildings, streets and pavements are inaccessible and restrict independent mobility for people with physical and sensory disabilities.”

The Public Source, a Beirut-based newsroom examined the failed government response in the aftermath of an ammonium nitrate explosion in Beirut that left hundreds of residents disabled.

The United Nations Disability Statistics is a clearinghouse for demographic data by country.

Last year, the Global Investigative Journalism Network published a guide to covering disabilities, including tips for finding data.

The Zero Project, a program of the Austrian-based Essl Foundation, is an initiative to support the implementation of the United Nations Convention on the Rights of Persons with Disabilities. The Zero Project database contains thousands of experts and organizations that can help explore disability issues worldwide.

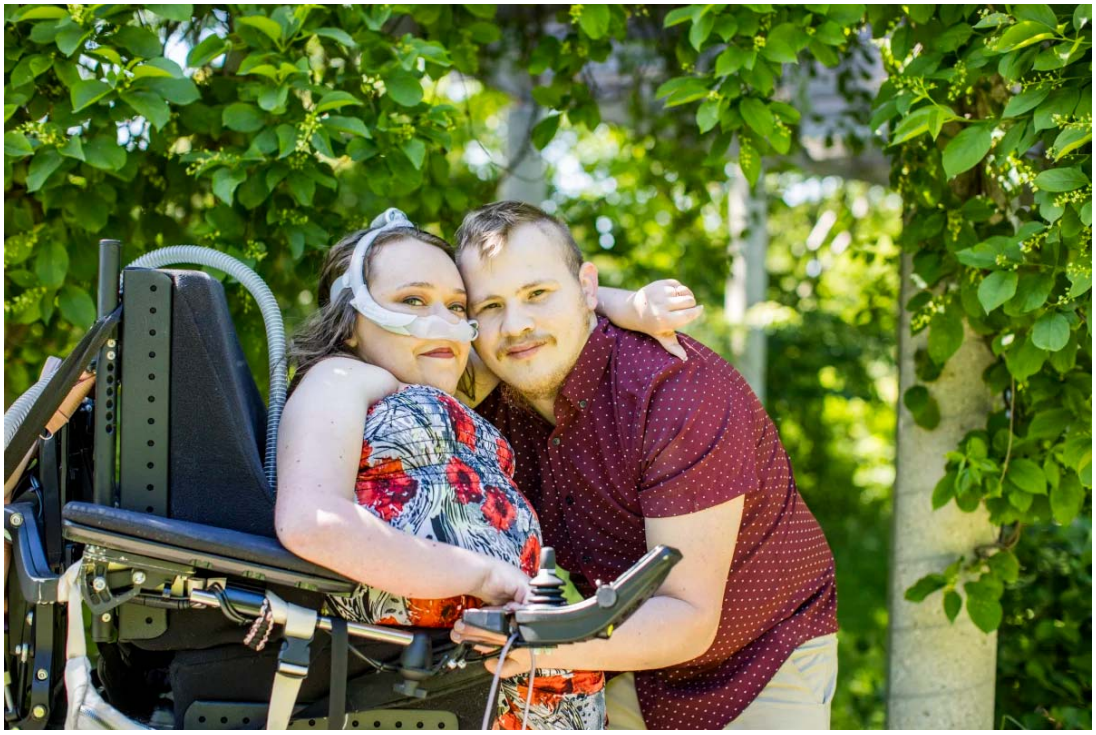
Keep digging

Be creative in seeking disability data.

Silverman — who has had to wrangle data to cover intellectual and developmental disability issues — urged reporters to "always, always, always try to get data and records from an individual, family member or other sources who has access to unredacted materials."

She also recommended talking with academics who might have data or going to another agency if one won't give you the data.

"If someone tries that hard to keep information from you, keep digging," she said. "It probably means you are onto something."



Amber Weise lost Supplemental Security Income and health insurance after marrying Devin. Joseph Shapiro reported how the federal program penalizes couples. NARAYAN MAHON / NPR

Disability Language Style Guide

Access the Spanish language translation of this guide here.

Spanish language guide PDF

You can also access a Romanian translation of the guide here.

You can also download the NCDJ Style Guide as a PDF.

As language, perceptions and social mores change rapidly, it is becoming increasingly difficult for journalists and other communicators to figure out how to refer to people with disabilities. Even the term “disability” is not universally accepted. This style guide, which covers dozens of words and terms commonly used when referring to disability, can help. The guide was developed by the National Center on Disability and Journalism at Arizona State University’s Walter Cronkite School of Journalism and Mass Communication and was last updated in the summer of 2021.

First, we would like to offer some basic guidelines:

- Refer to a disability only when it’s relevant to the story and, when possible, confirm the diagnosis with a reputable source, such as a medical professional or other licensed professional.
- When possible, ask sources how they would like to be described. If the source is not available or unable to communicate, ask a trusted family member, advocate, medical professional or relevant organization that represents people with disabilities.
- Avoid made-up words like “diversability” and “handicapable” unless using them in direct quotes or to refer to a movement or organization.
- Be sensitive when using words like “disorder,” “impairment,” “abnormality” and “special” to describe the nature of a disability. The word “condition” is often a good substitute that avoids judgement. But note that there is no universal agreement on the use of these terms -- not even close. “Disorder” is ubiquitous when it comes to medical references; and the same is true for “special” when used in “special education,” so there may be times when it’s appropriate to use them. But proceed with extra caution.
- Similarly, there is not really a good way to describe the nature of a condition. As you’ll see below, “high functioning” and “low functioning” are considered offensive. “Severe”

implies judgement; “significant” might be better. Again, proceed with caution. This is increasingly tricky turf.

Remember, our sources don’t always speak the way we write. That’s OK. You may end up using a derogatory term in a direct quote, but be certain that it’s fundamental to the story. Otherwise, paraphrase and use a more acceptable term.

In this guide, we urge reporters and other communications professionals to refer to a disability only when it’s relevant to the story being told. But what is “relevant” is not always clear. Should a story about residents complaining about noisy airplanes flying over their houses note that one of the residents who is complaining uses a wheelchair? Should someone who is blind be identified as such in a story about people who have been stranded while hiking and had to be rescued?

In the first case, we suggest the answer is “no.” The fact that someone uses a wheelchair does not make the airplane noise any more or less irritating. In the second case, the answer is “maybe.” If the hiker’s blindness contributed to him or her getting stranded, making note of that fact is relevant. If the person’s sight had nothing to do with the situation, leave it out.

People living with disabilities often complain, and rightly so, that their disability is mentioned even when the story has nothing to do with their disability.

A note about person-first language. In the past, we have encouraged journalists and others to use person-first language (such as, “a person who has Down syndrome” rather than “a Down syndrome person”) as a default. Even with the caveat that this does not apply to all, we have heard from many people with disabilities who take issue with that advice. For us, this really emphasizes the fact that no two people are the same -- either with regard to disabilities or language preferences. And so we are no longer offering advice regarding a default. Instead, we hope you will double down to find out how people would like to be described. We also will include some guidance in individual entries here -- but again, we encourage you to confirm on a case-by-case basis.

Another note -- this time about the language around COVID-19. The pandemic altered the way many people think about disability, as people who had never encountered such obstacles were suddenly unable to leave their houses. People with disabilities spoke out on social media about this, and “long haulers” now understand firsthand what some people with disabilities experience. The language around COVID-19 is evolving. The BBC and The Conversation both have well-considered takes on it. Archaeologist Elisa Perego coined the term “long COVID” to refer to people with lasting symptoms. This condition also has been called “long haul” and people with it, “long haulers.”

Writing about disability is complicated and requires sensitivity -- a must for any form of journalism that involves people. If you are in doubt about how to refer to a person, ask the person. And if you can’t ask the person, don’t avoid writing about disability. Use this guide. Do your best.

– Amy Silverman, NCDJ advisory board member

Special thanks to Rebecca Monteleone, University of Toledo; Jon Henner, University of North Carolina at Greensboro; Sherri Collins, Arizona Commission for the Deaf and Hard of Hearing; Sara Luterman; the NCDJ advisory board; and all the style guide readers who offered suggestions for this guide.

Able-bodied

Background: This term is used to describe someone who does not identify as having a disability. Some members of the disability community oppose its use because it implies that all people with disabilities lack “able bodies” or the ability to use their bodies well. They may prefer “non-disabled” or “enabled” as being more accurate.

NCDJ Recommendation: The term “non-disabled,” and the phrases “does not have a disability” or “is not living with a disability” are more neutral choices. “Able-bodied” is an appropriate term to use in some cases, such as when referring to government reports on the proportion of able-bodied members in the workforce. In some cases, the word “typical” can be used to describe a non-disabled condition, although be aware that some in the disability community object to its use.

AP style: Not addressed

Abnormal/abnormality

Background: “Abnormality” is a word used to describe a condition that deviates from what is considered normal. It can be appropriate when used in a medical context, such as “abnormal curvature of the spine” or an “abnormal test result.” However, when used to describe an individual, “abnormal” is widely viewed as derogatory. The phrase “abnormal behavior” reflects social-cultural standards and is open to different interpretations.

NCDJ Recommendation: The words “abnormal” or “abnormality” might be acceptable when describing scientific phenomena, such as abnormalities in brain function. However, avoid using such words to describe a person. Referring to someone who does not have a disability as a “normal person” implies that people with disabilities are deviant or strange. “Typical” can be a better choice. Be cautious when using the term “abnormal behavior.” Explain what it means in the context in which it is being used.

AP style: Not addressed

Addict/addiction

Background: Addiction “is a treatable, chronic medical disease involving complex interactions among brain circuits, genetics, the environment, and an individual’s life experiences. People with addiction use substances or engage in behaviors that become compulsive and often continue despite harmful consequences,” according to the American Academy of Pain Medicine.

Addiction often implies dependence on substances other than alcohol, although alcoholism is essentially alcohol addiction.

The American Psychiatric Association discourages using derogatory language such as the term "junkie" to refer to someone who misuses drugs.

According to the U.S. Department of Health and Human Services' Center for Substance Abuse Treatment, the word "addiction" is acceptable for uncontrollable, compulsive use of substances as well as acts such as gambling, sex, working, etc., in the face of negative health and social consequences. The Center states that addiction differs from dependence. Do not use the terms "addiction" and "dependence" interchangeably. "Addiction" usually refers to a disease or disorder; "dependence" may, on the other hand, describe babies born to mothers who use drugs or cancer patients who take prescribed painkillers. The center also recommends using the word "misuse" in place of "abuse" when describing harmful drug usage.

It's best to avoid using "clean" and "dirty" with regard to drug test results, according to the Center for Substance Abuse and Treatment. The terms are considered derogatory because they equate symptoms of illness to filth. When referring to a drug test, state that the person "tested positive for (drug)."

NCDJ Recommendation: "Addiction" is an acceptable term, although some prefer "substance abuse disorder." It is preferable to refer to someone who harmfully uses drugs as "someone with a drug addiction" rather than an "addict." Use "recovering" or "in recovery from" to refer to someone trying to overcome an addiction; that is, "someone recovering from a methamphetamine addiction."

Conforms to AP style. The AP also suggests avoiding words like "abuse" or "problem" in favor of the word "use" with an appropriate modifier such as "risky," "unhealthy," "excessive" or "heavy." "Misuse" also is acceptable. Don't assume all people who engage in misuse have an addiction. Avoid "alcoholic", "addict", "user" and "abuser" unless individuals prefer those terms for themselves or if they occur in quotations or names of organizations, such as Alcoholics Anonymous.

Afflicted with/stricken with/suffers from/victim of

Background: These terms carry the assumption that a person with a disability is suffering or has a reduced quality of life. Not every person with a disability suffers, is a victim or is stricken.

NCDJ Recommendation: It is preferable to use neutral language when describing a person who has a disability, simply stating the facts about the nature of the disability. For example: "He has muscular dystrophy."

Conforms to AP style that suggests avoiding "descriptions that connote pity."

Albino/albinism

Background: According to the Mayo Clinic, “albinism typically refers to oculocutaneous (ok-u-low-ku-TAY-nee-us) albinism (OCA) — a group of inherited disorders that results in little or no production of the pigment melanin. The type and amount of melanin your body produces determines the color of your skin, hair and eyes. Melanin also plays a role in the development of optic nerves, so people with albinism have vision problems. Signs of albinism are usually apparent in a person’s skin, hair and eye color, but sometimes differences are slight. People with albinism also are sensitive to the effects of the sun and are at increased risk of developing skin cancer.”

According to the National Organization on Albinism and Hypopigmentation (NOAH), there is debate over whether albinism is a disability, but it is often referred to as one because of issues associated with vision. Also, according to NOAH, the term albino has been used throughout history in a hateful way; therefore many prefer the people-first term, “person with albinism.”

NCDJ Recommendation: Refer to a person with albinism, rather than an albino.

AP style: The stylebook refers, without comment, to albino, albinos.

Alcoholic/alcoholism

Background: An alcoholic is someone who has the disease of alcoholism. Alcoholism is characterized by a loss of control in the use of alcohol, according to the American Psychiatric Association. The Center for Substance Abuse Treatment recommends using people-first language when referring to alcoholism, such as “someone with alcoholism” or “someone with an alcohol addiction.”

NCDJ Recommendation: Refer to someone who harmfully uses alcohol as “a person with alcoholism” rather than an “alcoholic,” which tends to identify someone solely by their disease. Use “recovering” to refer to someone with the disease of addiction, as in “someone recovering from alcoholism.”

Conforms to AP style

Alcoholics Anonymous

Background: Alcoholics Anonymous was founded in 1935 by Bill W. and Dr. Bob S. in Akron, Ohio, according to the AA General Service Office. AA is “a fellowship of men and women who share their experience, strength and hope with each other that they may solve their common problem and help others to recover from alcoholism,” according to the group’s preamble. AA members do not pay dues or fees; rather, the organization is supported by contributions. AA is unaffiliated with any outside organizations or institutions and does not endorse, finance or oppose any causes. The AA program is focused on 12 steps to achieve sobriety.

NCDJ Recommendation: Because anonymity is central to the organization, disclose that someone is a member of Alcoholics Anonymous only if it is essential to the story. When

covering AA, consider referring to members by their first names only unless official references or context requires otherwise. These same considerations apply when covering other 12-step programs, such as Narcotics Anonymous or Gamblers Anonymous.

AP style: Not addresses except in terms of abbreviation: AA is acceptable on second reference.

Americans with Disabilities Act (ADA)

Background: The Americans with Disabilities Act is federal civil rights legislation that was signed into law in 1990 to address discrimination on the basis of disability in employment, public accommodations, transportation and telecommunications as well as state and local government services.

NCDJ Recommendation: Use Americans with Disabilities Act on first reference; ADA is acceptable on second reference.

Conforms to AP style

American Sign Language (ASL)/signer/interpreter

Background: American Sign Language is a complete language that utilizes "signs made by moving the hands combined with facial expressions and postures of the body," according to the National Institute on Deafness and Other Communication Disorders. Many people in North America who are deaf or hard of hearing use it as a primary means of communication.

The terms "signer" and "interpreter" often are used interchangeably but mean different things. A signer is "a person who may be able to communicate conversationally with deaf persons but who may not necessarily possess the skills and expertise to accurately interpret complex dialogue or information," according to the Massachusetts Department of Health and Human Resources. "To become an interpreter, an individual must not only display bilingual and bicultural proficiency but also have the ability to mediate meanings across languages and cultures, both simultaneously and consecutively. This takes years of intensive practice and professional training."

NCDJ Recommendation: Specify American Sign Language on first reference, capitalizing all three words. ASL is acceptable on second reference. Use "interpreter" only for those who have completed advanced training. The Registry of Interpreters of the Deaf has a searchable database of registered interpreters.

AP style: Not addressed

See also Deaf

Amputation/amputee

Background: Amputation refers to the removal of a bodily extremity, usually during a surgical operation, for a variety of reasons, according to Johns Hopkins Medicine. People who have undergone an amputation are commonly referred to as "amputees," but the term may be offensive and often is not used correctly. Some people have a physical characteristic that is not a result of an amputation.

NCDJ Recommendation: "Someone with an amputation" is generally acceptable.

AP style: Not addressed

Attention-deficit/hyperactivity disorder (ADHD)

Background: ADHD, or attention-deficit/hyperactivity disorder, is a relatively common neurodevelopmental diagnosis. The American Psychiatric Association offers details about the condition, which often is diagnosed in children, with more boys affected than girls. Adults are also diagnosed with ADHD. Symptoms include restlessness, difficulty in focusing or staying organized and impulsivity. Those with an ADHD diagnosis may also exhibit difficulty sitting still or engaging in quiet activities.

NCDJ Recommendation: Refer to someone as having attention-deficit/hyperactivity disorder only if the information is relevant to the story and if you are confident the person has been medically diagnosed with the condition. Use "attention-deficit/hyperactivity disorder" on first reference; ADHD is acceptable on second reference.

Some people with ADHD prefer to say they "have" the condition; others prefer to say they "are" ADHD. Ask your sources for their preference; if that's not possible, consider using people-first language (the person has ADHD or has been diagnosed with ADHD).

AP style: Not addressed

Augmentative and alternative communication

See Facilitated communication

Autism/autism spectrum disorder/autistic

Background: Autism spectrum disorder is a group of complex disorders related to brain development, according to the National Institute of Mental Health. Common symptoms of autism spectrum disorder include difficulties in communication, impaired social interaction and restricted and repetitive patterns of behavior, interests or activities, according to the Institute. However, symptoms vary across the spectrum. Many experts classify autism as a developmental disability.

Prior to 2013, subtypes of autism, such as Asperger's syndrome, autism disorder and childhood disintegrative disorder, were classified as distinct disorders. The fifth edition of the American

Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders consolidates all autism disorders under the larger autism spectrum disorder diagnosis.

Opinions vary on how to refer to someone with autism. Some people with autism prefer being referred to as "autistic" or an "autistic person." Others object to using autistic as an adjective. The Autism Self Advocacy Network details this debate.

NCDJ Recommendation: Refer to someone as having autistic spectrum disorder only if the information is relevant to the story and if you are confident there is a medical diagnosis. Ask individuals how they prefer to be described. Many prefer to be described as "autistic," while others prefer "an autistic person" or a "person with autism."

AP style: The stylebook states that it's acceptable to use the word "autism" as "an umbrella term for a group of developmental disorders." It also says it is acceptable to use the word autism in stories. It does not address the use of autistic as an adjective.

Additional material: "I Don't Have Autism, I'm Autistic," Lenny Letter

Asperger's syndrome

See Autism

Behavioral health

See Mental illness

Bipolar disorder

Background: Bipolar disorder is a mental illness believed to be caused by a combination of genetic factors and neurological functioning, according to the National Institute of Mental Health. It is characterized by unusually intense shifts in emotion, energy, behavior and activity levels in what are called "mood episodes." Such episodes usually are classified as manic, hypomanic, depressive or mixed episodes. Bipolar disorder often develops during late adolescence or early adulthood.

NCDJ Recommendation: Refer to someone as having "bipolar disorder" only if the information is relevant to the story and you are confident there is a medical diagnosis. If a medical diagnosis is not available, use quotes around the term and indicate that a diagnosis has not been confirmed. Do not use "bipolar" as an adjective for something other than a medical condition as for example, when referring to something that rapidly or drastically changes.

AP style: Not directly addressed, although the style book recommends avoiding using disability-related words lightly or in unrelated situations.

See also Depression and Mental illness/mental disorder

Birth defect

See Defect/birth defect

Blind/legally blind/limited vision/low vision/partially sighted/visually impaired

Background: According to the American Foundation for the Blind, the term "legally blind" denotes a person with 20/200 visual acuity or less. Therefore, "blind" or "legally blind" is acceptable for people with almost complete vision loss. Many people with vision loss are not considered blind. The foundation recommends that, unless the person refers to himself or herself as legally blind, the terms "low vision," "limited vision" or "visually impaired" should be used. The foundation also publishes a glossary of eye conditions.

NCDJ Recommendation: Use "blind" only when the person has complete loss of sight and "legally blind" when the person has almost complete loss of sight. Other terms also may be acceptable. It is best to ask your sources what terms they prefer and take that into consideration. Commonly used terms include:

- Limited vision: Acceptable when a person is not legally or completely blind
- Low vision: Acceptable when a person is not legally or completely blind
- Partially sighted: Used most often in British publications but acceptable if a person is not legally or completely blind
- Visually impaired: Similar to the term "hearing impaired," some may object to it because it describes the condition as a deficiency.

AP style: Included in its "Disabled/Handicapped" entry, the stylebook describes blind as "a person with complete loss of sight" and suggests using the terms "visually impaired" or "person with low vision" for those who have some sight.

Brain injury/traumatic brain injury (TBI)

Background: The Centers for Disease Control define traumatic brain injury as "an injury that affects how the brain works."

NCDJ Recommendation: Use "person with a brain injury" or "person with a traumatic brain injury" rather than "brain damaged," which is considered derogatory.

AP style: Addressed in entry for "Trauma," suggesting that "traumatic brain injury" is an acceptable use of the word "trauma."

Caregiver/caretaker

Background: A caregiver is an individual who "provides direct care" to people with disabilities and others, according to the Merriam-Webster Dictionary. While "caregiver" and "caretaker"

often are used interchangeably, they imply something different. As retired clinical psychologist and disability rights advocate Katherine Schneider notes, “You take care of property… To people you give care.”

NCDJ Recommendation: “Caregiver” is preferable to “caretaker” when referring to the care of people.

Conforms to AP style

Catatonia/catatonic

Background: Catatonia is a state in which a person does not move and does not respond to others. According to *Psychology Today*, it is a rare condition that may be associated with other disorders, such as schizophrenia. It is often used informally to describe someone who is in a stupor-like condition.

NCDJ Recommendation: Refer to someone as “catatonic” only if it is part of a medical diagnosis. Avoid using it casually as it may be offensive and inaccurate.

AP style: Not addressed

Cerebral palsy

Background: Cerebral palsy refers to a number of neurological disorders that appear in infancy or early childhood and permanently affect body movement and muscle coordination, according to the National institute of Neurological Disorders and Stroke. It is not caused by problems in the muscles or nerves but by differences in parts of the brain that control muscle movement. People with cerebral palsy can exhibit a variety of symptoms. Spastic cerebral palsy is a common type of cerebral palsy in which the movements of people with the disorder appear stiff and jerky.

NCDJ Recommendation: It is acceptable to describe a person as “someone with cerebral palsy,” followed by a short explanation of what the condition entails. It is acceptable to refer to someone as “having spastic cerebral palsy,” but it is derogatory to refer to someone as “spastic” or “a spaz.” When describing specific symptoms, it is always best to ask the person what terms they prefer.

AP style: Not addressed

Chemical and/or electrical sensitivities

Background: The University of Kansas Research & Training Center on Independent Living describes these as “chronic medical conditions characterized by neurological impairment, muscle pain and weakness, respiratory problems and gastrointestinal complaints. Reactions for those with chemical sensitivities are triggered by low-level exposure to everyday substances and products, including pesticides, solvents, cleaning agents, new carpeting and adhesives, and

fragrances and scented products. Electrical sensitivities are triggered by electromagnetic fields from electrical devices and frequencies. These conditions also are called “toxicant-induced loss of tolerance,” “environmental illness” or “sick-building syndrome.”

NCDJ Recommendation: Use “person with chemical intolerance” or “people with environmental illness.” Do not use “chemophobic” as it is considered derogatory.

AP style: Not addressed

Chronic disease/chronic illness

Background: A chronic illness is defined by the National Health Council as a health condition lasting three months or longer and includes conditions such as cancer or heart disease. Many illnesses, such as diabetes or multiple sclerosis, are life-long conditions.

There is debate about when someone with a chronic illness is considered to have a disability.

NCDJ Recommendation: When referring to a person with a chronic illness, only refer to the condition if it is pertinent to the story you are confident there is a medical diagnosis. Ask your sources how they want to be described and, when in doubt, consider using people-first language, such as “person with diabetes” rather than “a diabetic.”

AP style: Not addressed

Cleft palate or lip/harelip

Background: The University of Kansas Research & Training Center on Independent Living describes this as a specific congenital disability involving the lip and gum. The Center recommends against using the term “harelip” as it is anatomically incorrect and stigmatizing.

NCJD Recommendation: Use “person who has a cleft palate.” Avoid “harelip.”

Conforms to AP style

Cochlear implant

Background: A cochlear implant is an electronic device that can improve understanding of speech for some people who are deaf or hard of hearing. The device does not fully restore hearing, but it gives a representation of sounds to help a person understand speech. It has been criticized by some in the Deaf community who are concerned that the device could threaten Deaf culture. However, advocates support the device for suitable candidates. (There are physical considerations that rule out cochlear implants for some.)

NCDJ Recommendation: When referring to a cochlear implant, avoid describing it as a corrective device or one that would restore a deaf person to mainstream society. Instead, define

it as an electronic device that can assist a person who is deaf or hard of hearing in understanding speech.

AP style: Not addressed

See also Deaf

Congenital disability

Background: A person who has a congenital disability has had a disability since birth. Common congenital disabilities include Down syndrome, heart-related medical conditions and most forms of cerebral palsy. “Congenital” is not interchangeable with “genetic,” as a genetic condition is present from birth but a congenital condition is not necessarily genetic.

NCDJ Recommendation: It is acceptable to state that someone has a congenital disability or lives with a congenital disability. Alternatively, it is acceptable to say that a person “has had a disability since birth” or “was born with a disability.” State the specific disability if possible. Avoid using “defect” or “defective” when describing a disability because the terms imply that the person is somehow incomplete or sub-par.

AP style: The style book states that “congenital disorder” is acceptable and recommends being specific about the condition.

Crazy/deranged/loony/mad/nuts/psycho/stir crazy

Background: These words were once commonly used to describe people with mental illness but are now considered offensive. They are still used in a variety of contexts but should be avoided.

NCDJ Recommendation: Do not use these words, particularly when reporting on mental illness, unless they are part of a quote that is essential to the story.

Conforms to AP style

See also Insane/mentally deranged/psychopathology

Cretin/cretinism

Background: The Merriam-Webster Dictionary defines cretininism as “a usually congenital condition marked by physical stunting and intellectual disability and caused by severe hypothyroidism” and goes on to say, “Chronic iodine deficiencies in diet can result in malfunctions of the thyroid gland, the gland that produces hormones necessary for normal human development. Some mountainous regions, such as parts of the Alps, do not naturally provide their inhabitants with a diet rich enough in iodine, and the resultant hypothyroidism causes stunted growth and mental retardation. In Franco-Provençal (the Romance speech of

French Switzerland and adjacent areas of France), a person affected by hypothyroidism was called a *cretin*, literally, “wretch, innocent victim,” The word meant simply “Christian” and emphasized the hypothyroid victim's basic humanity.”

NCDJ Recommendation: “Cretin” is considered a slur to describe a person with intellectual disabilities. Use the term “hypothyroidism” instead.

AP style: Not addressed

Cripple/crip

Background: Merriam-Webster defines the noun “cripple” as “a lame or partly disabled person or animal” and as “something flawed or imperfect.” It also is used as a verb. The word dates to Old English, where it was related to words that meant to “creep” or “bend over.” According to the blog grammarphobia.com, it became offensive in the early 20th century and was replaced by “handicapped” and then by “disabled.”

Recently, some disability activists have reclaimed the word. Jon Henner, an assistant professor at University of North Carolina at Greensboro, who is Deaf, describes himself as a “crip linguist.”

While some activists have embraced the word, adopting hashtags such as “#criplit” and “#cripthevote,” others are very much against its use. Keah Brown, a writer and disability activist who has cerebral palsy, tweeted in 2018: “I just really can’t stand the word cripple, so whenever I see it, I block it out. I legit ignore every notification with the word in it.”

NCDJ Recommendation: Avoid using “cripple” as either a noun or verb unless you are describing the “crip” movement or if it’s in a direct quote.

AP style: “Cripple” is considered offensive when used to describe a person who is lame or disabled.

Cued speech

Background: According to the Centers for Disease Control and Prevention, “cued speech” is “a building block that helps children who are deaf or hard-of-hearing better understand spoken languages.” It’s a series of hand signs and spots near the mouth used to differentiate between sounds that look the same as one is mouthing them. It is not interchangeable with American sign language; in fact, it’s not sign language at all. It can be used with babies and older children. Raisingdeafkids.org has a good list of related resources and more information.

NCDJ Recommendation: Because it is not commonly used, particularly in the U.S., include a definition when using the term.

AP style: Not addressed

Deaf

Background: It is first important to understand that many people do not consider being deaf or having hearing loss as a disability. Instead, deafness is often considered a culture. Some people with mild, moderate hearing loss may affiliate themselves with the Deaf community and prefer to be referred to as “deaf” instead of “hard of hearing.” Alternatively, some who are profoundly deaf may prefer the term “hard of hearing.”

“Deaf” and “hard of hearing” became the official terms recommended by the World Federation of the Deaf in 1991. Many people in the Deaf community prefer the use of a lowercase “d” to refer to audiological status and the use of a capital “D” when referring to the culture and community of Deaf people. The National Association of the Deaf has not taken a definitive stand on this issue.

NCDJ Recommendation: Lowercase when referring to a hearing-loss condition or to a deaf person who prefers lowercase. Capitalize for those who identify as members of the Deaf community or when they capitalize Deaf when describing themselves. “Deaf” should be used as an adjective, not as a noun; it describes a person with profound or complete hearing loss. Other acceptable phrases include “woman who is deaf” or “boy who is hard of hearing.” When quoting or paraphrasing a person who has signed their responses, it’s appropriate on first reference to indicate that the responses were signed. It’s acceptable to use the word “said” in subsequent references.

AP style: The stylebook uses “deaf” to describe a person with total hearing loss and “partially deaf” or “partial hearing loss” for others. It calls for use of a lower case “d” in all usages.

Deaf-blind, Deafblind or DeafBlind

Background: Indicates a person who has some loss of both vision and hearing. This also is referred to as deaf-blindness or deafblindness. Until recently, the term deaf-blind was widely accepted, and it is still in use today. For example, the National Center on Deaf-Blindness retains the hyphen. But according to deafblind.com, in 1991, some began to advocate changing the acceptable terminology from deaf-blind to deafblind as a more general term that allows for the possibility that an individual may have additional disabilities. Today, many government and private organizations in the U.S. and elsewhere use deafblind instead of deaf-blind.

NCDJ Recommendation: The terms deafblind, deafblindness, deaf-blind and deaf-blindness are all acceptable. However, whenever possible, ask the individual which term they prefer.

AP style: Not addressed

Deaf and dumb/deaf-mute

Background: “Dumb” was once widely used to describe a person who could not speak and implied the person was incapable of expressing himself or herself; it eventually came to be synonymous with “silent.”

“Deaf-mute” was traditionally used to refer to people who can neither speak nor hear in traditional ways. However, people with speech and hearing disabilities are capable of expressing themselves in writing, through sign language and in other ways. Additionally, a person who does not use speech may be able to hear.

NCDJ Recommendation: Avoid these terms as they often are used inaccurately and can be offensive. It is acceptable to refer to someone as deaf or hard of hearing. If possible, ask the person which is preferable. Mute and dumb imply that communication is not possible. Instead, be as specific as possible. If someone uses American Sign Language, lip-reads or uses other means to communicate, state that.

Conforms to AP style

Defect/birth defect

Background: A defect is defined as an imperfection or shortcoming. A birth defect is a physical or biochemical difference that is present at birth. Many people consider “defect” and other forms of the term offensive when describing a disability as they imply the person is deficient or inferior to others.

NCDJ Recommendation: Avoid using “defect” or “defective” when describing a disability. Instead, state the nature of the disability or injury.

AP style: The stylebook says “birth defect” is acceptable in broad references, such as lessening the chances of birth defects. But it should not be used when referring to a specific person or to a group of people with a specific condition. Instead, be specific about the condition and use only if relevant to the story. Some prefer the term congenital disorder.

Deformed/deformity

Background: A deformity is a condition in which part of the body does not have the typical or expected shape, according to Merriam-Webster Dictionary. Physical deformities can arise from a number of causes, including genetic mutations, various disorders, amputations and complications in utero or at birth. However, the word “deformity” has a negative connotation when used in reference to those with disabilities.

NCDJ Recommendation: Avoid using “deformed” as an adjective to describe a person.

AP style: AP medical stories tend to refer to a specific deformity or deformities rather than describing an individual as “deformed.”

Dementia/senility

Background: “Dementia” is “a general term for a decline in mental performance severe enough to interfere with daily life,” according to the Alzheimer’s Association. Dementia is not a specific

illness; it refers to a wide range of symptoms. Alzheimer's disease is the most common form of dementia. According to the National Institute on Aging, other dementias include Lewy body dementia, frontotemporal disorders and vascular dementia. The institute states, "It is common for people to have mixed dementia – a combination of two or more types of dementia. For example, some people have Alzheimer's disease and vascular dementia."

Other medical diagnoses associated with dementia include Creutzfeldt-Jakob disease, Huntington's disease, Parkinson's disease and Wernicke-Korsakoff syndrome (previously known as "wet brain").

Common symptoms across forms of dementia include memory loss, difficulty performing complex tasks, communication difficulties, personality changes and paranoia, according to the Mayo Clinic. In addition to their cognitive component, many types of dementia include physical symptoms, such as the abnormal eye movements of Huntington's disease or the tremors associated with Parkinson's disease.

Some organizations suggest avoiding the terms "demented," "dementing," "dements," "senile" or "senility" to refer to someone with dementia. The terms "senility" and "senile" denote conditions brought on by aging and often are used incorrectly to denote dementia.

NCDJ Recommendation: Refer to someone as having dementia only if the information is relevant to the story and you are confident there is a medical diagnosis. Use "a person with dementia" or "a person living with dementia" rather than "demented" or "senile." When possible, reference the specific disease, such as "someone with Huntington's disease." When referencing Huntington's disease or Parkinson's disease, use the full term rather than shortening to "Huntington's" or "Parkinson's."

AP style: Not addressed

Depression

Background: Depression is characterized by a loss of interest in activities, persistent fatigue, difficulty in concentrating and making decisions, prolonged feelings of emptiness or hopelessness, and abnormal eating habits, according to the National Institute of Mental Health. Its proper name is "major depressive disorder." The institute says that related diagnoses include seasonal affective disorder (characterized by the "onset of depression during the winter months"), psychotic depression (a combination of psychosis and depression), and postpartum depression (sometimes experienced by mothers after giving birth). Bipolar disorder used to be referred to as "manic depressive illness," but that is no longer the case.

NCDJ Recommendation: Refer to someone as having depression only if the information is relevant to the story and you are confident there is a medical diagnosis. If a medical diagnosis is not available, use quotes around the term and indicate that a diagnosis has not been confirmed. Specify the type of condition if it is known. The terms "depressed," "depressing" and

“depressive” are acceptable in other contexts when the person being referenced does not have a medically diagnosed condition. For example, “They found the election results depressing.”

AP style: The style book suggests naming the specific condition when possible rather than making a general reference. Use lower case unless referring to the Great Depression.

See also Bipolar disorder and Mental illness/mental disorder

Developmental disability/disabilities

Background: The Centers for Disease Control defines developmental disabilities as “a group of conditions (that arise) due to an impairment in physical, learning, language or behavior areas. These conditions begin during the developmental period of life, may impact day-to-day functioning, and usually last throughout a person’s lifetime.”

By definition, developmental disabilities manifest before age 22. Those with such disabilities often require lifelong or extended support. Examples of developmental disabilities include autism spectrum disorder, spina bifida, cerebral palsy and intellectual disabilities. Legal definitions vary from state to state. A developmental disability can include a long-term physical or cognitive/intellectual disability or both.

NCDJ Recommendation: While it is acceptable to use the terms “developmental disability” and “developmental disabilities,” it is preferable to use the name of the specific disability whenever possible.

Conforms to AP style

Differently-abled

Background: This term came into vogue in the 1990s as an alternative to “disabled,” “handicapped” or “mentally retarded.” Currently, it is not considered appropriate (and for many, never was). Some consider it condescending, offensive or simply a way of avoiding talking about disability. Others prefer it to “disabled” because “dis” means “not,” which means that “disabled” means “not able.” But particularly when it comes to referring to individuals, “differently abled” is problematic. As some advocates observe, we are all differently abled.

NCDJ: “Person with a disability” is a more neutral term than “differently-abled.”

AP style: The style book suggests avoiding the term and, instead, trying to be specific about the disability.

See also Disabled/disability

Disabled/disability

Background: “Disability” and “disabled” generally describe functional limitations that affect one or more of the major life activities, including walking, lifting, learning and breathing. Various laws define disability differently.

NCDJ Recommendation: While it is usually acceptable to use these terms, keep in mind that disability and people who have disabilities are not monolithic. Avoid referring to “the disabled” in the same way that you would avoid referring to “the Asians,” “the Jews” or “the African Americans.” When describing individuals, do not reference disabilities unless it is clearly pertinent to the story. When possible, refer to a person’s specific condition.

AP style: “Disabled” is described as a general term for a physical, mental, developmental or intellectual disability. Avoid describing someone as “handicapped.”

See also Disabled people/people with disabilities

Disability Studies

Background: The Society for Disability Studies defines the discipline as “sitting at the intersection of many overlapping disciplines in the humanities, sciences and social sciences. Programs in Disability Studies should encourage a curriculum that allows students, activists, teachers, artists, practitioners, and researchers to engage the subject matter from various disciplinary perspectives.”

NCDJ Recommendation: Use Disability Studies in the same way you would reference other academic disciplines.

AP style: Not addressed

Disabled people/people with disabilities

Background: The phrased “disabled people” is an example of identity-first language (in contrast to people-first language). It is the preferred terminology in Great Britain and by a number of U.S. disability activists. Syracuse University’s Disability Cultural Center says, “The basic reason behind members of (some disability) groups’ dislike for the application of people-first language to themselves is that they consider their disabilities to be inseparable parts of who they are.” For example, they prefer to be referred to as “autistic,” “blind” or “disabled.”

Several U.S. disability groups have always used identity-first terms, specifically the culturally Deaf community and the autistic rights community.

NCDJ Recommendation: Ask the disabled person or disability organizational spokesperson about their preferred terminology.

AP style: Conforms to AP style, which adds that in describing groups of people, or when individual preferences cannot be determined, use person-first language.

Disfigurement/disfigured

Background: According to the University of Kansas Research & Training Center on Independent Living, "disfigurement refers to physical changes caused by burns, trauma, disease or congenital conditions."

NCDJ Recommendation: Do not call someone "disfigured" as it is considered derogatory. Refer specifically to the physical changes.

AP style: Not addressed

Dissociative identity disorder/multiple personality disorder

Background: Dissociative identity disorder is characterized by the emergence of two or more distinct personality states or identities in a person's behavior or consciousness, according to the National Alliance on Mental Illness. These personalities, medically known as "alters," can exhibit different speech patterns, mannerisms, attitudes, thoughts, gender identities and even physical characteristics. Other symptoms include memory loss, emotional issues, disorientation and the development of other mental disorders.

NCDJ Recommendation: Refer to someone as having "dissociative identity disorder" only if the information is relevant to the story and if you're confident there is a medical diagnosis. Use the term "dissociative identity disorder," not "multiple personality disorder," and avoid the acronym "DID." Consider using people-first language, such as "a person with dissociative identity disorder."

AP style: Not addressed

Diversabled/Diversability

Background: "Diversability" is a term coined by Tiffany Yu, a disability rights advocate. Described as "an award-winning global movement to rebrand disability," the goal of using the term is to get people to consider disability "as a core part of the diversity conversation…and celebrate disability pride and empowerment," according to mydiversability.com.

NCDJ Recommendation: When writing about Tiffany Yu's group, use "Diversability" as a proper name. Otherwise, use the terms "disabled," "disability" or "person with a disability."

AP style: Not addressed

Down syndrome

Background: Down syndrome is a congenital condition caused by the presence of an extra full or partial copy of chromosome 21 in an individual's cell nuclei. It was first reported in 1866 by Dr. John Langdon Down and is characterized by a range of physical and cognitive

characteristics, which the National Institutes of Health details. Down syndrome is the most common chromosomal condition.

Other terms commonly used to refer to people with Down syndrome include “intellectually disabled,” “developmentally disabled” and a person who has a “cognitive disability” or “intellectual disability.” The Global Down Syndrome Foundation considers all of these terms acceptable, while the National Down Syndrome Society suggests using “cognitive disability” or “intellectual disability.” Down syndrome also can be referred to as Trisomy 21. Historically it was called “mongoloidism,” and people with it were called Mongoloids; this is now considered offensive.

NCDJ Recommendation: The proper term for the disorder is Down syndrome, not Down’s syndrome or Down’s Syndrome. (The proper terminology in the United Kingdom is Down’s syndrome). Consider using people-first language, stating that someone is “a person with Down syndrome” or “has Down syndrome.” Avoid using terms such as “suffers from” or “afflicted with” in association with the condition.

The terms “intellectually disabled,” “developmentally disabled,” “cognitive disability” and “intellectual disability” are acceptable when used in a people-first context to describe someone with Down syndrome, such as “the person has a developmental disability.” However, it is more accurate to refer specifically to Down syndrome when that is the medically diagnosed condition.

Conforms to AP style

See also *Mentally retarded* *and* *Mongoloid*

Dwarf/little person/midget/short stature

Background: Dwarfism is a medical or genetic condition that results in a stature below 4’10,” according to Little People of America. The average height of a dwarf is 4’0.”

Use of the word “dwarf” is considered acceptable when referring to the genetic condition, but it is often considered offensive when used in a non-medical sense.

The term “midget” was used in the past to describe an unusually short and proportionate person. It is now widely considered a derogatory slur. Little People of America has a statement on “the M word.”.

The terms “little people” and “little person” refer to people of short stature and have come into common use since the founding of the Little People of America organization in 1957. The appropriateness of the terms is disputed by those within and outside of the organization. However, Little People of America recommends using the descriptors “short stature,” “little person” or “someone with dwarfism.”

NCDJ Recommendation: Only refer to a person’s short stature if it is relevant to the story. It is best to ask people which term they prefer to describe them. Use the term “dwarf” only when

applied to a medical diagnosis or in a quote. Avoid the terms “vertically challenged” and “midget.”

AP style: Dwarf is the “preferred term for people with a medical or genetic condition resulting in short stature.” “Midget” is considered offensive. The plural of “dwarf” is “dwarfs.”

Dyslexia/dyslexic

Background: Dyslexia is a learning disability characterized by challenges identifying speech sounds and learning how to connect them to letters and words, according to the Mayo Clinic. Its chief symptoms include difficulties with spelling, reading, pronunciation of words and processing auditory information. It is a common learning disability among children, although adolescents and adults with dyslexia often exhibit symptoms as well.

The term “dyslexic” is used by some organizations as a noun and as an adjective in a non-pejorative way; however, using the word as a noun (describing a person as a “dyslexic”) appears to be falling out of use.

NCDJ Recommendation: Refer to someone as having dyslexia only if the information is relevant to the story and if you’re confident there is a medical diagnosis. If a medical diagnosis is not available, use quotes around the term and indicate that a diagnosis has not been confirmed. Consider using people-first language, stating that someone “has dyslexia” rather than referring to him or her as “a dyslexic person.” Avoid using “dyslexic” as a noun, as in, “She is a dyslexic.”

AP style: Not addressed

Epilepsy/epileptic/epileptic fit

Background: Epilepsy is a chronic neurological and developmental disorder characterized by “recurrent, unprovoked seizures,” according to the Epilepsy Foundation. Originally called “falling sickness” in English, the word has roots in Greek and Latin.

Epilepsy manifests differently in individuals: The severity of epileptic seizures, their occurrence rates and the emergence of other health problems differ from person to person. Epilepsy is most commonly treated with medication but treatment also can include use of medical devices, surgery, diet and emerging therapy methods.

WebMD explains the difference between epilepsy and seizures in this way: “Seizures, abnormal movements or behavior due to unusual electrical activity in the brain, are a symptom of epilepsy. But not all people who appear to have seizures have epilepsy, a group of related disorders characterized by a tendency for recurrent seizures.”

NCDJ Recommendation: Refer to someone as having epilepsy only if the information is relevant to the story and if you’re confident there is a medical diagnosis. Consider using

people-first language, stating that someone “has epilepsy” or “has been diagnosed with epilepsy” rather than referring to him or her as an “epileptic.” The term “seizure” is preferred when referring to the brief manifestation of symptoms common among those with epilepsy. Do not say the person “had a fit” or “had an epileptic fit.”

AP style: Not addressed

See also Seizure

Facilitated communication

Background: Facilitated communication is a widely criticized communication technique that was popular in the 1990s. The technique was originally developed to help those with significant developmental disabilities, such as some forms of autism and cerebral palsy. A nonverbal person would theoretically communicate with the help of a facilitator by typing on a keyboard, pointing to an image, or pointing to letters on an alphabet board. However, academics eventually found there was little scientific evidence that the technique worked, leading many to conclude the aide was actually the one communicating, according to a study from Emory University.

In an official position statement, the American Speech-Language-Hearing Association warns that any messages extracted from facilitated communication “should not form the sole basis for making any diagnostic or treatment decisions.” Other organizations, including the American Psychological Association and the International Society for Augmentive and Alternative Communication also oppose facilitated communication. However, some people still strongly support the method.

It is important to note that “augmentative and alternative communication” – a general term used to refer to alternative methods that allow for written and spoken expression – is considered very different from facilitated communication. It is widely viewed as legitimate and important.

NCDJ Recommendation: Avoid language that may legitimize facilitated communication. When writing about it, specify that major disability organizations do not recognize facilitated communication as a valid communication technique.

AP style: Not addressed

Freak/freak show

Background: The Merriam-Webster Dictionary defines “freak” as “one that is markedly unusual or abnormal, such as a person or animal having a physical oddity and appearing in a circus sideshow.” This particular use of the word dates to the middle of the 19th century.

NCDJ Recommendation: Do not use the term “freak” to describe a person with a disability as it is derogatory.

AP style: Not addressed

Genetic defect/genetic disorder

Background: According to the National Human Genome Research Institute, a genetic disorder is "caused in whole or in part by a change in the DNA sequence away from the normal sequence. Genetic disorders can be caused by a mutation in one gene (monogenic disorder), by mutations in multiple genes (multifactorial inheritance disorder), by a combination of gene mutations and environmental factors, or by damage to chromosomes (changes in the number or structure of entire chromosomes, the structures that carry genes)."

Some of the more common genetic conditions include cystic fibrosis, Huntington's disease, and sickle cell anemia.

A genetic condition is congenital, but a congenital condition is not necessarily genetic. The Genome Research Institute offers comprehensive information about different genetic conditions, genetic testing and other pertinent topics.

NCDJ Recommendation: Avoid terms like "disorder" or "defect," which are considered derogatory. Instead use the word "condition" and try to identify the specific diagnosis if possible.

AP style: Not addressed, although the stylebook uses the term "disorder" to describe a range of conditions.

Gifted/twice exceptional

Background: According to the National Association for Gifted Children, giftedness is characterized by the capacity to perform above the level of one's peers. Others, including the authors of "Great Minds and How to Grow Them," question whether there is such a thing as a gifted child.

Another commonly used term is "twice exceptional" or "2E," which refers to a child with a disability who also is diagnosed as gifted. According to the National Association for Gifted Children, "Twice-exceptional learners are students who give evidence of the potential for high achievement capability in areas such as specific academics, general intellectual ability, creativity, leadership and/or visual, spatial or performing arts and also give evidence of one or more disabilities as defined by federal or state eligibility criteria, such as specific learning disabilities, speech and language disorders, emotional/behavioral disorders, physical disabilities, autism spectrum or other health impairments, such as ADHD. Twice-exceptional students represent a unique group of learners with diverse programming and emotional needs due to the fact that they may have both gifts and disabilities."

NCDJ Recommendation: Avoid describing people as "gifted" or "twice exceptional" unless they have been identified as such by a professional.

AP style: Not addressed

Handicap/handicapped/handicapable

Background: Merriam-Webster Dictionary defines handicap as "a physical disability (as a bodily impairment or a devastating disease)." The term has fallen out of favor in the disability community. In 2009, the writers of the television show "Glee" introduced the term "handicapable" as a positive alternative to other ways of referring to people with disabilities. However, its use is relatively rare and not generally accepted.

NCDJ Recommendation: Avoid using "handicap" and "handicapped" when describing a person. Instead, refer to the person's specific condition or use "person with a disability." The terms are still widely used and generally acceptable when citing laws, regulations, places or things, such as "handicapped parking," although many prefer the term "accessible parking." Avoid "handicapable."

Conforms to AP style with regard to "handicap" and "handicapped." The stylebook does not address "handicapable."

Hard of hearing

Background: The term "hard of hearing" may be used to refer to people who have a mild to moderate hearing loss that may or may not be corrected with amplification. Those who are hard of hearing usually use verbal speech to communicate. According to the University of Washington,, "hard of hearing" may refer to any hearing condition that can be helped by an auditory device.

"Deaf" and "hard of hearing" became the official terms recommended by the World Federation of the Deaf in 1991. Many people in the Deaf community and organizations, including the National Association of the Deaf, support the use of these terms. Some people with mild or moderate hearing loss may affiliate themselves with the Deaf community and prefer the term deaf. Alternatively, some who are deaf and don't have a cultural affiliation to the Deaf community may prefer the term "hard of hearing."

NCDJ Recommendation: "Hard of hearing" is almost always acceptable. However, use the term the person prefers if it's possible to ask.

AP style: Not addressed except to recommend using "hard of hearing" without hyphens unless it is an adjective directly preceding a person. However, AP advises against the latter formulation.

See also Deaf

Hearing impaired/hearing impairment

Background: The terms “hearing impaired” and “hearing impairment” are sometimes used to describe people with hearing loss that ranges from partial to complete. Many dislike the terms because “hearing impaired” describes a person in terms of a deficiency or what they cannot do. The World Federation of the Deaf has taken the stance that “hearing impaired” is no longer an acceptable term.

NCDJ Recommendation: Do not use “hearing impaired” or “hearing impairment.” For those with total hearing loss, “deaf” is acceptable. For others, “partial hearing loss” or “partially deaf “is preferred. Some might want to be called “hard of hearing.” It is best to ask your sources which terms they prefer.

AP style: The style book defers to the National Association of the Deaf, stating: “Hearing-impaired” was a well-meaning term that is not accepted or used by many deaf and hard of hearing people.”

See also Deaf

High functioning/low functioning

Background: “High functioning” and “low-functioning” are terms used to describe ability levels for people with a variety of conditions, including neurodiversity, intellectual disabilities and mental illness. Many people with intellectual disabilities and their advocates consider these terms to be dismissive or reductive of a person’s abilities. For example, “emotional intelligence” also is important when considering a person’s overall intelligence, according to the American Psychological Association.

Journalists should consider other ways of describing a person’s ability to function in society. For example, they might say that an individual with Down syndrome lives with minimal or no extra l assistance.

The term “high-functioning autism” is widely used but is not a medical diagnosis, and many consider it offensive.

NCDJ Recommendation: Avoid using the terms “high functioning” and “low functioning.” Instead, use medical diagnoses and describe an individual’s abilities and challenges, rather than using less-specific labels.

AP style: Not addressed

Homebound/housebound

Background: The two terms often are used interchangeably. According to the Merriam Webster Dictionary, homebound means “confined to the home.” The Office of Veteran’s Affairs uses the term “housebound” to describe those who spend most of their time in their home because of a disability or when someone is “permanently and substantially confined to their immediate

premises.” However, the terms are sometimes applied incorrectly to people with disabilities who require some mobility assistance but who are relatively independent. Disability advocacy groups emphasize that it is important not to assume people are homebound if they are disabled. Many feel that it’s never appropriate to use “homebound” or “housebound.”

NCDJ Recommendation: Avoid using the terms unless used in a direct quote.

AP style: Not addressed except to state that homebound and housebound are one word with no hyphens.

Identity-first language

Background: Identify-first language contrasts with people-first language. With identity-first language, the disability is mentioned first. For example, “Down syndrome girl” or “autistic boy.” An example of people-first language is “a girl with Down syndrome” or “a boy with autism.” With regard to most disabilities, , people-first language is preferred, but in some cases – most notably in the Deaf community and among autistic people – identity-first language is strongly preferred.

NCDJ Recommendation: Ask the person with the disability how they would like to be described. If that’s not possible, ask a spokesperson for the organization representing the relevant disability for preferred terminology.

Conforms to AP style

Infantile paralysis/poliomyelitis/polio/post-polio syndrome

Background: Infantile paralysis is shorthand for poliomyelitis and was commonly used in the past to describe polio. Its symptoms include muscle weakness and paralysis. Jonas Salk introduced the polio vaccine in the 1950s, which drastically reduced cases of polio in the U.S.

According to the University of Kansas Research & Training Center on Independent Living, “post-polio syndrome is a condition that affects some persons who have had poliomyelitis (polio) long after recovery from the disease. It is characterized by new muscle weakness, joint and muscle pain and fatigue.”

NCDJ Recommendation: Use the term polio rather than infantile paralysis. It is preferable to say, “He had polio as a child;”“She contracted polio as an adult,” or “He has post-polio syndrome” rather than “He suffers from polio” or “He is a victim of polio.”

Conforms to AP style

Injury/injuries

Background: “Injury” is commonly used to describe any harm or damage to an individual as the result of an accident or other event. It is frequently used in such references as “injuries suffered in a car accident.”

NCDJ Recommendation: Refer to injuries as being “sustained” or “received” rather than “suffered,” as “suffer” implies that an injured person is a victim or somehow less than a person who has not been injured. Use of “sustain” or “receive” removes the implied judgment.

AP style: The stylebook says injuries may be “suffered,” “sustained” or “received,”

Insane/insanity/mentally deranged/psychopathology

Background: The terms “insane,” “insanity” and “mentally deranged” are commonly used informally to denote mental instability or mental illness but can be considered offensive. The medical profession favors use of the terms “mental disorder” or “psychopathology.” In U.S. criminal law, insanity is a legal question, not a medical one.

NCDJ Recommendation: Use the term “mental illness” instead of “insane” or “mentally deranged,” except in a quote or when referring to a criminal defense.

Conforms to AP style

Insane asylum/mental health hospital/psychiatric hospital

Background: Hospitals that cared for people with various mental illnesses, often for long periods of time, were once commonly referred to as insane asylums. The term has largely gone out of use and is now considered objectionable and inaccurate.

NCDJ Recommendation: “Behavioral health hospital” or “psychiatric hospital” are the preferred terms to describe medical facilities specifically devoted to treating people with mental health conditions.

Conforms to AP style

See also Insane/insanity/mentally deranged/psychopathology

Intellectual disabilities/intellectually disabled

Background: An intellectual disability involves “significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills,” according to the American Association on Intellectual and Developmental Disabilities. There is debate over how relevant IQ tests should be in making a diagnosis.

NCDJ Recommendation: Both terms are acceptable, although consider using people-first language, stating that someone is “a person with an intellectual disability” rather than referring to the person as intellectually disabled.

Conforms to AP style

Interabled

Background: The term interabled is used by some in the disability community to refer to couples in which one person has a disability and the other does not. Proponents of the term say it helps to destigmatize relationships between people with disabilities and people without disabilities. Certain communities, such as the Muscular Dystrophy community and the Spinal Muscular Atrophy community, have embraced the term, but others argue that interabled relationships are relationships just like any other and should not be marked as different.

NCDJ Recommendation: Since the term is not in widespread use, its meaning should be explained for a general audience; ask sources how they prefer to describe their relationships whenever possible.

AP style: Not addressed except as it relates to hyphenation. In general, there is no hyphen after inter, so interabled is the correct usage (not inter-abled).

Invalid

Background: The Oxford English Dictionary defines an invalid as “a person made weak or disabled by illness or injury.” It is probably the oldest term for someone living with physical conditions that are considered seriously limiting. However, it is such a general term that it fails to accurately describe a person’s condition and is now widely viewed as offensive in that it implies that a person lacks abilities.

NCDJ Recommendation: Avoid using “invalid” to describe a person with a disability except in a direct quote.

AP style: Not addressed

Invisible disabilities

Background: The majority of people with disabilities have chronic conditions that are invisible or hidden. Although many in the general public associate disability with people using wheelchairs or white canes or who are missing limbs, more people have conditions that can’t be seen but are defined as disabilities under the 1990 Americans with Disabilities Act.

For example, millions of Americans are hard of hearing but most do not use sign language and many do not use hearing aids. Mental illness is a prevalent invisible disability. Many chronic

health conditions also are considered invisible disabilities, depending on their severity and impact on daily living.

Chronic illnesses such as Parkinson's disease, diabetes, lupus or Crohn's disease may fall into the category of invisible disabilities.

NCDJ recommendation: Do not apply the term "invisible disability" to people without asking what they prefer. Many people with chronic illnesses do not consider themselves disabled and thus may be offended by the term. If a preference is unknown, specify the condition rather than referring to it as a "hidden disability," which is vague and open to interpretation.

AP style: Not specifically addressed, but the style book suggests not using such terms without asking for an individual's preference.

Lame/lamebrain

Background: Lame is a word commonly used to describe difficulty walking as the result of an injury to the leg. Many people object to the use of the word to describe a physical condition because it is used in colloquial English as a synonym for weak, as in: "That's a lame excuse."

The Merriam-Webster Dictionary defines "lamebrain" as "a dull-witted person."

NCDJ Recommendation: Avoid using "lame" or "lamebrain" to describe a person except in a quote. In the case of a leg injury, explain instead that an injury resulted in difficulty walking.

AP style: Not addressed

Learning disability

Background: According to the University of Kansas Research & Training Center on Independent Living, learning disability "describes a neurologically based condition that may manifest itself as difficulty learning and using skills in reading (called dyslexia), writing (dysgraphia), mathematics (dyscalculia) and other cognitive processes due to differences in how the brain processes information. Individuals with learning disabilities have average or above average intelligence, and the term does not include a learning problem that is primarily the result of another cause, such as intellectual disabilities or lack of educational opportunity."

NCDJ Recommendation: Use "learning disability" when you're confident there is a medical diagnosis. If a medical diagnosis is not available, use quotes around the term and indicate that a diagnosis has not been confirmed. Do not substitute "slow learner" or another derogatory term like "retarded."

AP style: Not addressed

Little person/little people

See Dwarf, little person/people/midget/short stature

Mental illness/mental disorder

Background: "Mental illness" is an umbrella term for many different conditions that affect how individuals act, think, feel or perceive the world.. The most common forms of mental illness are anxiety disorders, mood disorders and schizophrenia disorders. Severity and symptoms vary widely. For more information on mental illness, see the National Institute for Mental Health.

Because of perceived stigma, some people are calling for an end to the use of the term "mental illness," suggesting instead "a person diagnosed with a psychiatric disorder" or "a person with a mental health history." Some advocates suggest using the term "mental health experience." However, the term "mental illness" still is widely used within the medical and psychiatric professions.

The American Psychiatric Association offers a useful media guide of appropriate terms. The association recommends using people-first language to describe mental illness in order to avoid defining people by their disability. "She experiences symptoms of psychosis" is preferable to "She is psychotic." "He is living with bipolar disorder" is preferable to "He is bipolar."

The terms "mental illness" and "mental disorder" are not interchangeable. Healthyplace.com has a good discussion of the differences.

NCDJ Recommendation: Refer to an individual's mental illness only when it is relevant to the story and you're confident there is a medical diagnosis. Whenever possible, specify the specific illness a person has rather than mental illness in general. Always refer to someone with a mental illness as a person first. Use quotes when officials or family members use a term such as "a history of mental illness" to refer to an individual, and when appropriate, indicate that the diagnosis has not been confirmed.

Conforms to AP style: The stylebook cautions against describing an individual as mentally ill unless clearly pertinent to a story and the diagnosis is properly sourced. Specific disorders should be used and the source of the diagnosis identified whenever possible. The stylebook also warns against drawing a connection between mental illness and violent crime and recommends that any source used to characterize a criminal suspect's mental health history should have the authority to speak on the matter. Finally, it cautions against "using mental health terms to describe non-health issues. Don't say that an awards show, for example, was "schizophrenic."

Mental health professional/shrink

Background: There are a number of types of mental health professionals. The following broad definitions are sourced from *Psychology Today*:

- Psychiatrist: A mental health professional able to prescribe psychotropic medications. Some provide emotional therapy as well as medication management.
- Psychoanalyst: A specific type of psychotherapist trained to work with both an individual's unconscious and unconscious mind. The field was founded by Sigmund Freud.
- Psychologist: A mental health professional trained in the discipline of psychology and who often does psychological testing and research.
- Psychotherapist: An umbrella term for mental health professionals trained to treat people for their health problems.

NCDJ Recommendation: Ask professionals how they should be identified, based on their formal training. Avoid using the word "shrink" in reference to a mental health professional except in a quote.

AP style: Not specifically addressed, but the style book refers to "mental health professional" in an entry on mental illness.

Mentally retarded

Background: The terms "mentally retarded," "retard" and "mental retardation" were once common terms that are now considered outdated and offensive. In 2010, President Barack Obama signed a measure known as "Rosa's Law" that replaced the term "mental retardation" with "intellectual disability" in many areas of government, including federal law.

From "My Heart Can't Even Believe It: A Story of Science, Love and Down Syndrome," (Amy Silverman, Woodbine House, 2016):

> "The word retarded has a slang-free history. For a long time, it simply meant slow.
>
> According to the Oxford English Dictionary, it's derived from the Italian word ritardato, and the first definition of the adjective version is 'held back or in check; hindered, impeded; delayed, deferred.'
>
> It's traced to religion in 1636 ('he to his long retarded Wrath gives wings'); to medicine in 1785 ('Polypus, sometimes obstructs the vagina, and gives retarded labour'); and later to politics ('Arguably, the legacy of communism manifests itself most acutely in the retarded economic development of the east').
>
> It also means 'characterized by deceleration or reduction in velocity,' as in a 1674 reference: 'When it hath passed ye vertex ye motion changeth its nature, & turneth from an equably accelerated into an equably retarded motion.'
>
> Actual references to retarded intelligence did not come until the turn of the 20th century, with the advent of the IQ test. Then numbers were assigned to words – not just 'mentally retarded,' but also terms like 'imbecile,' 'idiot' and 'moron'."

NCDJ Recommendation: Do not use the term retarded or other iterations. If you are going to use it in a quote, consider that decision carefully, as the word is particularly charged. Instead, always try to specify the type of disability being referenced. Otherwise, the term "intellectually disabled" is acceptable. Consider using people-first language, as in "a person with an intellectual disability" rather than "an intellectually disabled person." As always, ask the person which terms they prefer.

At times, words that are considered outdated may be appropriate because of the story's historical context. In those cases, attribute the term or note its historic use. For example, "The doctor said he was retarded, a term widely used at the time."

AP style: "Mentally retarded" should be avoided. The stylebook suggests using terms such as "mentally disabled," "intellectually disabled" and "developmentally disabled."

See also Intellectual disabilities/intellectually disabled

Midget

See Dwarf, little person/midget/short stature

Mongoloid

Background: The term was commonly used in the late 19th century to refer to people who had Down syndrome, due to the similarity of some of the physical characteristics of the disorder to Eastern Asian people, who were called Mongoloid, according to the Oxford English Dictionary. It is considered highly derogatory to describe someone with Down syndrome as being "mongoloid."

NCDJ Recommendation: Avoid the use of "mongoloid" to refer to someone with Down syndrome. Even in the case of a direct quote, consider how offensive the term is and include the historical context if possible.

AP style: Not addressed

See also Down syndrome

Multiple personality disorder

See Dissociative identity disorder/multiple personality disorder

Muscular dystrophy (MD)

Background: Muscular dystrophy could refer to any of more than 30 genetic conditions characterized by progressive weakness and degeneration of the muscles that control

movement, according to the National Institute of Neurological Disorders and Stroke. Onset could be in infancy, childhood, middle age or later.

NCDJ Recommendation: It is acceptable to describe a person as "someone with muscular dystrophy" or "someone living with muscular dystrophy," followed by a short explanation of what the condition entails. Avoid saying a person "suffers from" or "is afflicted with" the disease. MD is acceptable on second reference.

AP style: Not addressed, although AP does not use the abbreviation MD.

Non-disabled

Background: "Non-disabled" refers to someone who does not have a disability. According to the University of Kansas Research & Training Center on Independent Living, "Non-disabled is the preferred term when the context calls for a comparison between people with and without disabilities. Use 'non-disabled' or 'people without disabilities' instead of healthy, able-bodied, normal or whole."

NCDJ Recommendation: "Non-disabled" or "does not have a disability" are acceptable terms when referring to people who do not identify as having a disability. In general, avoid using "able-bodied' except in a quote.

AP style: Not addressed

See also Able-bodied

Neurodiversity

Background: The Oxford English Dictionary defines neurodiversity as "the range of differences in individual brain function and behavioral traits, regarded as part of the normal variation in the human population (used especially in the context of autism spectrum disorders)." The word was coined in the late 1990s.

Neurodiversity basically means that brains operate differently – and that's not a bad thing. There is an advocacy movement around this concept, and discussion of the "neurodiversity paradigm." From the blog neurocosmopolitanism.com: "The idea that there is one 'normal' or 'healthy' type of brain or mind, or one 'right' style of neurocognitive functioning, is a culturally constructed fiction, no more valid…than the idea that there is one 'normal' or 'right' ethnicity, gender or culture."

"Neurotypical" refers to a person who is considered part of the normal variation in the human population.

It is important to note that some autism advocates do not like this term; it tends to be embraced by self advocates but not as frequently by families of people with autism who also have intellectual disabilities and other challenges.

NCDJ Recommendation: "Neurodiversity" can be used as a way of describing someone on the autism spectrum, but because it's a relatively new term, consider offering the definition when you use it, particularly in work meant for a mainstream audience. Remember that not everyone in the autism community prefers the term.

AP style: Not addressed

Nonspeaking/nonverbal

Background: According to the blog Autistictic, non-speaking means "not using oral speech to communicate," while non-verbal means "not using words to communicate." Both terms are unpopular with advocates, particularly those who are non-speaking because of the relationship to facilitated communication. The preference is to ask the person or someone who knows them for the exact description of their communication skills and preferences.

NCDJ Recommendation: Avoid using either term except in a direct quote. Ask the person or someone who knows them how they would like to be described.

AP style: Not addressed except in terms of hyphenation. The general rule is not to hyphenate when using a prefix with a word starting with a consonant (nonverbal and nonspeaking)

See also: Facilitated communication

Obsessive-compulsive disorder (OCD)

Background: Obsessive-compulsive disorder is an anxiety disorder characterized by unreasonable thoughts and fears that lead to repetitive and often ritualized behaviors or compulsions. OCD may present as a fear of contamination, disarray or intrusion, according to the Mayo Clinic. People with OCD usually exhibit both obsessions and compulsions but sometimes exhibit only one or the other. OCD is often treated with pharmaceutical drugs, psychotherapy methods, or a combination of the two.

NCDJ Recommendation: Refer to someone as having OCD only if the information is relevant to the story and you're confident there is a medical diagnosis. If a medical diagnosis is not available, use quotes around the term and indicate that a diagnosis has not been confirmed. Do not use OCD as an adjective for someone who obsesses over certain things but has not been formally diagnosed with the disorder. Use "obsessive-compulsive disorder" on first reference; OCD is acceptable in second reference.

AP style: Not addressed

Paraplegia/paraplegic

Background: Paraplegia is defined as the loss of movement in the lower extremities and torso. It is typically caused by a spinal cord or brain injury. Referring to someone as a “paraplegic” is offensive to some people as it implies that their condition defines them.

NCDJ Recommendation: Avoid referring to an individual as a paraplegic. Instead, say the person has paraplegia. Sometimes people with paraplegia refer to themselves as a “para.” In those cases, use the word in quotes.

AP style: Not specifically addressed, but AP refers to paraplegia in its general disability entry.

Partial hearing loss/partially deaf

Background: “Hard of hearing” is the most common term for those who have a mild to moderate hearing loss that may or may not be corrected with amplification.

NCDJ Recommendation: Ask your sources what term they prefer. Otherwise, “hard of hearing” is almost always acceptable.

AP style: The stylebook recommends using “partial hearing loss” or “partially deaf” for those who have some hearing loss.

See also Deaf; Cochlear implant and Hard of hearing

Patient/sick

Background: Members of the disability community argue that characterizing people with a disability as “sick” or referring to them as “patients” signals there is something unwell about them or that they are in need of medical attention, when, in fact, that is often not the case.

NCDJ Recommendation: Avoid referring to someone with a disability as “sick” or to their disability as a “sickness.” If a person is receiving medical treatment, then the word “patient” is appropriate; however, it should be avoided outside of a medical context.

AP style: Not addressed

People-first language

Background: People-first language avoids defining people in terms of their disability. In most cases, this entails placing the reference to the disability after the reference to a person, as in “a person with a disability,” or “a person living with a disability,” rather than “the disabled person.”

The National Center on Birth Defects and Developmental Disabilities of the Centers for Disease Control & Prevention offers an easy-to-follow guide on people-first language.

People-first language is not preferred by all people with disabilities. Specifically, some members of the autism and Deaf communities prefer identity-first language.

NCDJ Recommendation: Ask the person with a disability how they prefer to be described; if that's not possible, ask a spokesperson for the organization representing the relevant disability for preferred terminology.

Conforms to AP style

See also Identity-first language

Plain English

The Center for Inclusive Design defines Plain English as "a direct style of writing for people who can read at a reasonable level. It helps people who want to read and understand information quickly. Plain English is sometimes known as plain language or Everyday English. Plain English looks and sounds like standard forms of writing." Another version, Easy English, aims at a lower reading level with short sentences often accompanied by pictures.

NCDJ Recommendation: Use Plain English or Plain Language but confirm with the source that that is the correct terminology. It might be Easy English.

AP style: Not addressed

Post-traumatic stress disorder (PTSD)

Background: Post-traumatic stress disorder is an anxiety disorder usually caused by an extremely emotional traumatic event. Such events may include assault, war, sexual assault, natural disasters, car accidents or imprisonment. Symptoms may include reliving the traumatic event, avoidance of certain behaviors, negative emotions, or physical symptoms such as dizziness or nausea.

NCDJ Recommendation: Refer to someone as having PTSD only if the information is relevant to the story and you're confident there is a medical diagnosis. "Post-traumatic stress disorder" is correct on first reference; use PTSD on second reference. The term "flashback" may be used to denote reliving an event that triggered the PTSD.

AP style: PTSD is acceptable on either first or second reference but should be spelled out at least one time. Many medical organizations do not use a hyphen when spelling "posttraumatic;" however the AP does.

Prelingually deaf/postlingually deaf/late-deafened

Background: "Prelingually deaf" refers to individuals who were born deaf or became deaf prior to learning to understand and speak a language, according to Gallaudet University, a university for the education of the deaf and hard of hearing in Washington, D.C. "Postlingually deaf" or "late-deafened" describes people who lost their hearing ability after they learned to speak a language.

NCDJ Recommendation: All the terms are acceptable, although, because they are not widely used, an explanation is required for a general audience.

AP style: Not addressed

See also Deaf

Psychotic/psychosis

Background: Psychosis is a broad term used to describe symptoms of certain mental health problems that include delusions or hallucinations or other loss of contact with reality. People with psychosis are described as psychotic. In common usage, “psychotic” often is used in the same way as the word “crazy,” and thus can be offensive and inaccurate.

NCDJ Recommendation: Use the words “psychotic” and “psychosis” only when they accurately describe a medical experience. Avoid using “psychotic” as an adjective to describe a person; instead refer to a person as “having a psychotic condition” or “experiencing a psychosis.” Avoid using the terms colloquially.

AP style: Not directly addressed, although the style book recommends avoiding using disability-related words lightly or in unrelated situations.

See also Mental illness/mental disorder

Quadriplegia/quadriplegic

Background: Quadriplegia is defined as the paralysis of all four limbs as well as the torso. It often is caused by a spinal cord or brain injury and is characterized by the loss of sensory and motor function. People with these conditions often are referred to as “quadriplegics” and “paraplegics,” but these terms are considered offensive by some. “Tetraplegia” is used interchangeably with “quadriplegia.”

NCDJ Recommendation: Consider using people-first language, such as “a person with quadriplegia,” or “a person living with quadriplegia” rather than “quadriplegic,” since the latter implies that the condition defines them. Sometimes people with quadriplegia refer to themselves as “quads.” In these cases, use in quotes.

AP style: Not addressed

See also Tetraplegia/tetraplegic

Retarded

See Mentally Retarded

Schizophrenia/schizophrenic

Background: Schizophrenia is a serious chronic mental illness characterized by distorted recognition and interpretations of reality, affecting how an individual thinks, feels and acts, according to the National Institute of Mental Health. Common symptoms include visual and auditory hallucinations, delusional and disordered thinking, unresponsiveness, and a lack of pleasure in daily life and other social issues. It does not involve split personalities. Less than one percent of the general population has schizophrenia, and it is treated mostly through the use of pharmaceutical drugs.

NCDJ Recommendation: Refer to someone as having schizophrenia only if the information is relevant to the story and you're confident there is a medical diagnosis. If a medical diagnosis is not available, use quotes around the term and indicate that a diagnosis has not been confirmed. Consider using people-first language, stating that someone is "a person with schizophrenia," "a person living with schizophrenia," or "a person diagnosed with schizophrenia" rather than a "schizophrenic" or "a schizophrenic person." Do not use the word "schizophrenic" colloquially as a synonym for something inconsistent or contradictory.

AP style: Schizophrenia is classified as a mental illness. The stylebook cautions against using mental health terms to describe non-health issues. "Don't say that an awards show, for example, was schizophrenic."

Seizure

Background: According to the Mayo Clinic: **"**A seizure is a sudden, uncontrolled electrical disturbance in the brain. It can cause changes in your behavior, movements or feelings, and in levels of consciousness. If you have two or more seizures or a tendency to have recurrent seizures, you have epilepsy. There are many types of seizures, which range in severity. Seizure types vary by where and how they begin in the brain. Most seizures last from 30 seconds to two minutes. A seizure that lasts longer than five minutes is a medical emergency. Seizures are more common than you might think. Seizures can happen after a stroke, a closed head injury, an infection such as meningitis or another illness. Many times, though, the cause of a seizure is unknown."

NCDJ Recommendation: Do not say someone has had a seizure unless there has been a medical diagnosis. If a medical diagnosis is not available, use quotes around the word and indicate that a diagnosis has not been confirmed. Do not assume that a person who has had a seizure has epilepsy.

AP style: Not addressed

See also Epilepsy/epileptic/epileptic fit

Service animal/assistance animal/guide dog/Seeing Eye dog

Background: Service animals are trained animals, usually dogs, that provide services to people with disabilities. They also are sometimes called “assistance animals,” “guide dogs,” or “Seeing Eye dogs.”

The federal definition of a “service animal” applies to “any guide dog, signal dog or other animal trained to do work or perform tasks for the benefit of an individual with a disability.” This may include animals that guide individuals with impacted vision, alert individuals with impacted hearing to intruders or sounds, provide minimal protection or rescue work, pull a wheelchair or fetch dropped items. If they meet this definition, animals are considered service animals under the ADA, regardless of whether they have been licensed or certified. For more information, consult the U.S. Department of Justice Civil Rights Division Disability Rights Section.

NCDJ Recommendation: The terms “service animal,”” assistance animal” and “guide dog” all are acceptable. Avoid use of “Seeing Eye dog” as Seeing Eye is a registered trademark of The Seeing Eye school in Morristown, N.J. Be aware that licensure and/or certification of service animals is a contentious issue in the disability community, so it may be best to refer to the federal definition.

AP style: Although there is no entry for service animal, the style book takes note of the Seeing Eye dog trademark and says “guide dog” is prefered in all references.

Short stature

See Dwarf, little person/midget/short stature

Spastic/spaz

See Cerebral palsy

Special/special needs/functional needs

Background: The term “special needs” was popularized in the U.S. in the early 20th century during a push for special needs education to serve people with all kinds of disabilities. The word “special” in relationship to those with disabilities is now widely considered offensive because it euphemistically stigmatizes that which is different.

The term “special education” is still widely used when referring to public school programs, although some government entities use titles like “exceptional student services.”

NCDJ Recommendation: Avoid using these terms when describing a person with a disability or the programs designed to serve them, with the exception of government references or formal names of organizations and programs. It is more accurate to cite the specific disability or disabilities in question. The term “functional needs” is preferred when a term is required. For example, “addressing the functional needs of people with disabilities” could be used when referring to a facility or program.

Don't use the term "SPED" as shorthand for special education. It's considered offensive.

AP style: The style book urges avoidance of the term "special education" and suggests trying to be specific about the needs or services in question.

Spina bifida

Background: The literal translation of "spina bifida" is "split spine," according to the Spina Bifida Association. The condition is a neural tube defect that occurs when the spinal column does not close all the way in the womb. It is the most common neural tube defect in the U.S. There are four types of spina bifida. The Spina Bifida Association publishes a list of terms and definitions.Complications from spina bifida range from minor physical problems to significant intellectual and physical disabilities.

NCDJ Recommendation: It is acceptable to describe a person as "someone with spina bifida" or "someone living with spina bifida," followed by a short explanation of what their condition entails, if it is pertinent to the story.

AP style: Not addressed

Stuttering/stammering/childhood-onset fluency disorder

Background: Stuttering is a speech disorder characterized by repeated or prolonged words, sounds or syllables that affect the flow or fluency of speech, according to the National Institute on Deafness and Other Communication Disorders. Stuttering often is involuntary and can be accompanied by rapid blinking or lip tremors. Stuttering symptoms typically manifest in early childhood. While many children outgrow stuttering, a small percentage of adults stutter as well. The American Speech-Language-Hearing Association notes that most stuttering can be treated by behavioral therapies.

There is some ambiguity about the difference between stuttering and stammering and which term is appropriate in different contexts. However, organizations such as the National Institute on Deafness and Other Communication Disorders, the Mayo Clinic and the National Stuttering Association generally use the term "stuttering" to refer to the speech disorder. The Diagnostic and Statistical Manual of Mental Disorders debuted the new term "childhood-onset fluency disorder" to refer to stuttering, along with a few new criteria for its diagnosis. However, this term is not widely used.

NCDJ Recommendation: The word "stuttering" is preferred over "stammering." Instead of referring to an individual as "a stutterer;" say "a person who stutters." Refer to stuttering only if it is relevant to the story. Avoid "childhood-onset fluency disorder" without explanation.

AP style: Not addressed

Suffers from/victim of/afflicted with/stricken with

Background: These terms carry the assumption that a person with a disability is suffering or has a reduced quality of life. Not every person with a disability suffers, is a victim or is stricken.

When renowned scientist Stephen Hawking died in 2018, media accounts referred to him as "finally free" of the wheelchair he used for decades. The references angered disability rights advocates, who argued that Hawking achieved remarkable success while using a wheelchair and a computerized voice system, not despite those devices.

NCDJ Recommendation: It is preferable to use neutral language when describing a person who has a disability, simply stating the facts about the nature of the disability. For example: "He has muscular dystrophy," and avoiding characterizing those conditions as afflictions.

Conforms to AP style that suggests avoiding "descriptions that connote pity."

Suicide

Background: The World Health Organization recommends avoiding language that sensationalizes or normalizes suicide or presents it as a solution to problems. For example, the terms "failed attempt" or "successful" or "completed attempt" depict suicide as a goal, project or solution. Some argue that the term "commit" implies that suicide is a criminal act, while others view the term "commit" as neutral.

NCDJ Recommendation: The NCDJ endorses The Associated Press style, below.

AP style: Avoid using "committed suicide" except in direct quotations from authorities. Alternate phrases include "killed himself," "took her own life" or "died by suicide." The verb "commit" with "suicide" can imply a criminal act. Laws against suicide have been repealed in the U.S. and many other places. Do not refer to an "unsuccessful suicide attempt." Refer instead to an "attempted suicide."

"Medically assisted suicide" is permitted in some states and countries. Advocacy groups call it "death with dignity" or "right-to-die," but AP does use those phrases on their own. When referring to the legislation whose name includes "death with dignity," "right-to-die" or similar terms, say the law or proposal allows 'the terminally ill to end their own lives.' If the term is in the name of a bill or law, make that clear. 'Euthanasia' should not be used to describe 'medically assisted suicide' or 'physician-assisted suicide'." The AP also suggests using resources from www.reportingonsuicide.org.

Survivor/battle

Background: Some use the term "survivor" to affirm their recovery from or conquest of an adverse health condition. Common usages include "cancer survivor," "burn survivor," "brain injury survivor" or "stroke survivor." However, the terms are disliked by some because they imply that those who die simply did not fight hard enough. For similar reasons, there is disagreement

about characterizing disease or illness as a “battle,” as in “to battle cancer.” These arguments surfaced after U.S. Senator John McCain died in the summer of 2018.

NCDJ Recommendation: Terms such as “battle” and “survivor” are still widely accepted and understood, but the user should be aware that they could offend some people.

AP style: The style book suggests using the term “survivor” with care because it can be imprecise, among other reasons.

Tetraplegia/tetraplegic

Background: Tetraplegia, used interchangeably with quadriplegia, is defined as the paralysis of all four limbs as well as the torso. It often is caused by a spinal cord or brain injury and is characterized by the loss of sensory and motor function. Paraplegia is similar but does not affect the arms. People with these conditions often are referred to as “quadriplegics” and “paraplegics,” but these terms are considered offensive by some.

NCDJ Recommendation: Consider using people-first language, such as “a person with tetraplegia” rather than tetraplegic, since this implies that the condition defines them.

AP style: Not addressed

See also Quadriplegia

Triggers/content warnings

Background: Psychological triggers are words, images or sounds that activate phobias, panic attacks or flashbacks to unpleasant events or trauma. The concept of triggering originated with early psychoanalytical diagnoses of posttraumatic stress disorder, called “war neuroses,” in WWI veterans. News reports covering sensitive topics, such as abuse, assault, addiction, suicide, combat and violence, frequently contain descriptive scenarios that can deeply effect audiences. Some content can spark difficult memories for people with certain mental illnesses and phobias. Trigger warnings communicate that upcoming content may produce unpredictable and unwelcome reactions for some readers. They give audiences a choice on whether or not to proceed with consuming the information. However, some readers object to trigger warnings and view them as patronizing and stifling to academic freedom.

NCDJ Recommendation: If you’re an educator, consider alerting students ahead of time if content contains graphic descriptions of traumatic events. Journalists also may want to include such warnings in material distributed to a general audience. Triggers can be hard to predict, and they vary from individual to individual, but communicating the nature of your content builds audience trust. Refrain from using the term “trigger warning” in a flip or casual way.

AP style: The style book suggests a content warning at the top of stories when the subject matter may be considered offensive or disturbing, but the story does not contain quoted

profanity, obscenities or vulgarities. For example: “Eds: Graphic details of the killings could be offensive or disturbing to some readers.”

Tourette syndrome/Tourette’s syndrome/Tourette’s disorder

Background: Tourette syndrome is a neurological disorder characterized by tics, sudden, purposeless and rapid movements or vocalizations, according to the National Institute of Neurological Disorders. Such tics are recurrent, involuntary and non-rhythmic. The disorder was originally named for French neurologist Dr. Georges Gilles de la Tourette, who first described the condition in 1885, according to the National Institute of Neurological Disorders and Stroke.

While those with Tourette syndrome often can suppress tics by focusing on them, the disorder also can be treated with medication, relaxation techniques and therapy. Although involuntary cursing is commonly thought to be a key trait of the disorder, only a minority of those with Tourette syndrome exhibit this symptom.

Terminology for the disorder is varied. It is interchangeably referred to as “Tourette syndrome,” “Tourette’s syndrome” and “Tourette’s disorder.” However, prominent mental health organizations such as the Mayo Clinic, the Centers for Disease Control and Prevention, and the Tourette Syndrome Association, refer to it as “Tourette syndrome.”

NCDJ Recommendation: Use “Tourette syndrome” with no possessive or capitalization of “syndrome.” Refer to someone as “having Tourette syndrome” only if the information is relevant to the story and if you’re confident there has been a medical diagnosis. Consider using people-first language, stating that someone is “a person with Tourette syndrome” or “a person diagnosed with Tourette syndrome.” Avoid the acronym TS, as it is not widely known.

AP style: The AP merely defines Tourette Syndrome as, “A neurological disorder characterized by involuntary, repetitive movements and vocalizations.”

Treatment/treatment center/rehab center/detox center

Background: Treatment is defined by the American Society of Addiction Medicine as the use of any planned, intentional intervention in the health, behavior, personal and/or family life of an individual living with alcoholism or another drug dependency designed to achieve and maintain sobriety, physical and mental health and maximum functional ability. A treatment center is an establishment usually run by psychiatric or medical professionals.

NCDJ Recommendation: “Treatment” is an acceptable term for medical interventions, and “treatment center” is acceptable for the establishment in which such practices take place. Use “treatment center” in place of “rehab” or “detox” center. A person enrolled in a treatment center should be referred to as a patient.

AP style: Not addressed

Vegetative state/vegetable/comatose/non-responsive

Background: The Merck Manual defines vegetative state as the absence of responsiveness or consciousness in which patients show no awareness of their environment. Patients may exhibit eye movements and other involuntary movements. A minimally conscious state is one in which a patient has some awareness of self and/or the environment.

NCDJ Recommendation: It is preferable to use a medical professional's diagnosis or, if that is not possible, terms such as "comatose" or "non-responsive." Avoid referring to someone as "a vegetable" or "veg" as such words dehumanize the person. The term "vegetative state" is preferable to "vegetable" or "veg," but it is considered offensive by some and is frequently misused.

AP style: The stylebook allows the use of "vegetative state," describing it as "a condition in which the eyes are open and can move, and the patient has periods of sleep and periods of wakefulness, but remains unconscious, unaware of self or others."

Wheelchair-bound/confined to a wheelchair

Background: People who use mobility equipment such as a wheelchair, scooter or cane consider the equipment part of their personal space, according to the United Spinal Association. People who use wheelchairs have widely different disabilities and varying abilities.

NCDJ Recommendation: It is acceptable to describe a person as "someone who uses a wheelchair," followed by an explanation of why the equipment is required. Avoid "confined to a wheelchair" or "wheelchair-bound" as these terms describe a person only in relationship to a piece of equipment. The terms also are misleading, as wheelchairs can liberate people, allowing them to move about, and they are inaccurate, as people who use wheelchairs are not permanently confined to them but are transferred to sleep, sit in chairs, drive cars, etc.

Conforms to AP style

National Center on Disability and Journalism

How the media cover disabilities

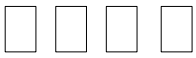
Jennifer LaFleur, UC Berkeley,

National Center for Disability and Journalism

1

What I'll cover

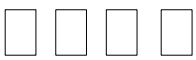
- Teach journalism at UC Berkeley's Graduate School of Journalism
- Previously was an investigative editor at several nonprofit newsrooms: Center for Public Integrity, Reveal, ProPublica
- Started covering disability issues because so few people were reporting those stories



2

What I'll cover

- National Center for Disability and Journalism
- Disability journalism
- Best practices
- Resources



3

National Center for Disability and Journalism

- Founded in 1998 by Suzanne Levine in San Francisco to improve and increase disability coverage
- Moved to Arizona State University's Cronkite School in 2008
- Launched contest, style guide, fellowships and trainings



4

Why stories are important

- More than **25%** of the US population has a disability.
- But ableism —stereotypes and harmful narratives about disability — are still rampant.
- Lots of opportunities for reporting on disability issues.
- For many years, coverage was limited.
- Now there are more stories addressing policies/systems.
- But understanding systems is complicated.

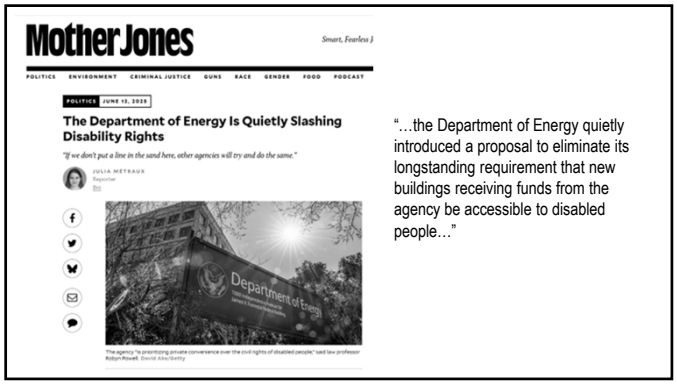
5

Disability stories exist on nearly every "beat"

- Public policy
- Environment
- Education
- Transportation
- Housing
- Health care
- Entertainment

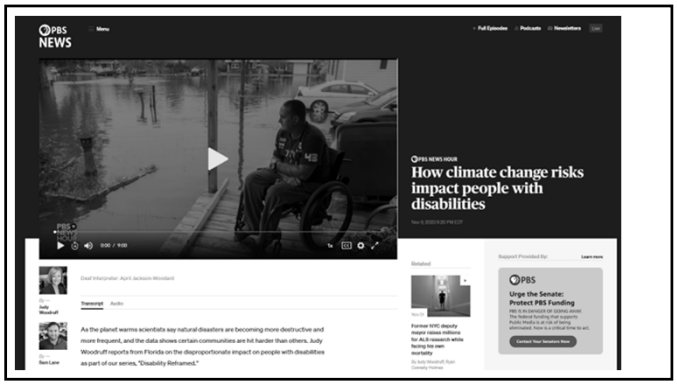


6



"…the Department of Energy quietly introduced a proposal to eliminate its longstanding requirement that new buildings receiving funds from the agency be accessible to disabled people…"

7



8



9

Transportation

Flying Blind, Kelechukwu Ogu





Critics call buses unreliable for those with disabilities

Bi-State's failure to provide reliable buses overloads van service for riders

10

BuzzFeed News
REPORTING TO YOU

The Private Equity Giant KKR Bought Hundreds Of Homes For People With Disabilities. Some Vulnerable Residents Suffered Abuse And Neglect.



11



An NPR investigation of SSI — a program run by the Social Security Administration — found that many disabled people get caught by this "marriage penalty," a left-over rule from decades ago when government policies didn't account for disabled people finding love and getting married.

NPR interviewed dozens of people who rely on SSI but, as a result, say they are stuck because of the program's treatment of those who marry.

www.npr.org/2024/06/18/g-s1-4991/social-security-ssi-marriage-penalty

12


PROPUBLICA
Graphics & Data
Newsletters
About
Nursing Homes Get Old for Many With Disabilities
Save at Apple
Shop now
FOLLOW PROPUBLICA
STAY INFORMED
ST. LOUIS — Melody Plog never thought she would be trying to move out of a nursing home.
She lived in a St. Louis apartment for 19 years and worked as an accountant until two years ago, when she lost her job. Plog, who has multiple sclerosis, couldn't find new work. When her

13


KQED
'I'd Be Left Alone': Medicaid Cuts Put Disabled Patients' In-Home Care at Risk
After Congress approved roughly $1 trillion in Medicaid cuts over the next decade, California advocates are worried about the future of home-based care covered by Medi-Cal.

14


EDUCATION
Trump administration reverses stance on integration of people with disabilities
OCTOBER 1, 2026 · 5:00 AM ET
HEARD ON ALL THINGS CONSIDERED
Jonaki Mehta
4-Minute Listen
PLAYLIST
TRANSCRIPT
DISABILITY RIGHTS ARE HUMAN RIGHTS
Hundreds of disability advocates gathered in New York in 2025 to protest cuts to Medicaid and demand the enforcement of disability rights protections.

15

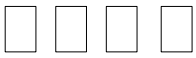
Common misconceptions

- People with disabilities can't speak for themselves.
- Disability is a weakness.
- Disability is a super power.
- Disability is something people want to or need to overcome.
- Accessibility and accommodations are special favors or need to be earned.
- Facilities/programs/websites don't have to be accessible.
- The views/positions of the disability community are the same.

16

NCDJ Style Guide

- Developed to provide consistent guidance on disability language
- In consultation with journalists and disability community
- Regularly updated
- Translated into multiple languages
- Comparison to other style guides with disagreements noted



17

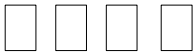
Language choices

- Refer to the disability only when it's relevant to the story.
- Use accurate language, referring to a specific diagnosis when possible.
- Use neutral language, avoiding implications that disability is inherently bad ("has" vs. "suffers from") .
- If it is relevant to the story, ask the person how they would like their disability to be characterized.
- Avoid "special needs" because the needs for accommodations are not special treatments or favors.

18

Language choices

- Person-first language puts the person before their disability ("people with disabilities;" "children with Down syndrome").
- Identity-first language puts the disability at the center ("disabled people;" "autistic students").
- If you're not sure what language to use, ask.



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Confined to a wheelchair or wheelchair-bound

- Describe a person only in relationship to a piece of equipment.
- They are misleading, as wheelchairs can liberate people, allowing them to move about.
- They are inaccurate, as people who use wheelchairs are not permanently confined in them, but transfer to sleep, sit in chairs, drive cars, etc.

20

Style guide

Mental illness is an umbrella term for many different conditions that affect how individuals act, think, feel or perceive the world. The most common forms of mental illness are **anxiety disorders**, **mood disorders**, and **schizophrenia disorders**.

NCDJ Recommendation: Refer to an individual's mental illness only when it is relevant to the story and the diagnosis comes from a proper source. **Whenever possible, specify the specific illness a person has rather than mental illness in general.**

AP style: The stylebook cautions against describing an individual as mentally ill unless clearly pertinent to a story and the diagnosis is properly sourced. **Specific disorders should be used and the source of the diagnosis identified whenever possible.**

21

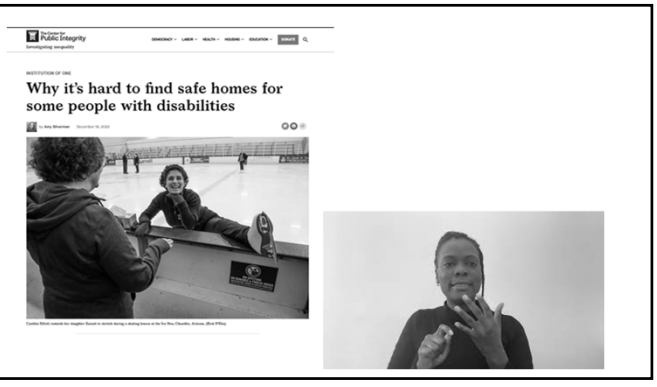
People-centered stories

22

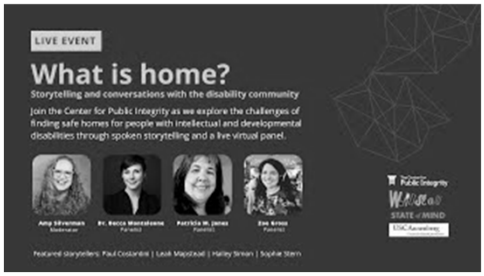
Sourcing

- For years, the disability community was covered without having a voice
- Nothing about us without us.
- Efforts to make stories accessible to disabled audiences; alt txt, plain language, asl
- Mention disability only when relevant to the story

23



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ProPublica: Arizona Promised to Help People With Developmental Disabilities. But Some Had to Wait a Long Time. Some Did Not Get Help at All.



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BuzzFeed News: Some People With Disabilities Were Abused And Neglected After Global Company KKR Took Over More Than 600 Group Homes



Translation done by Sandy Mislow of the Self-Advocacy Association of New York State. She can be reached at: sandy.mislow@gmail.com

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Data analysis helps us explore systemic issues

- Disability benefits data for adults and children receiving
- Workforce training funding for people with disabilities from the U.S. Department of Labor
- World Bank Disability Data Hub
- U.S. Department of Education, Civil Rights Data Collection
- U.S. Census data

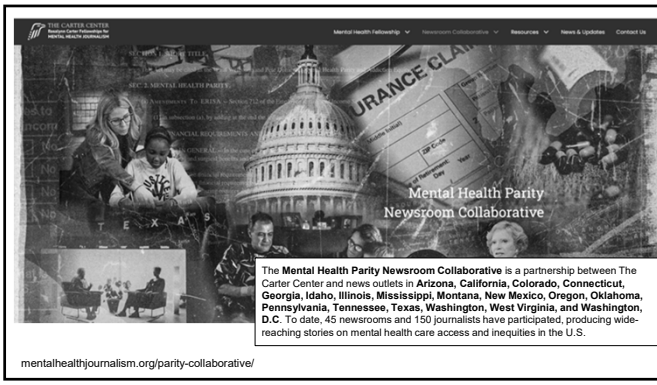
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Resources

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Global Investigative Journalism Network
Menu
Donate
Illustration: Alexandra Ramirez for GIJN
Guide to Investigating Disability Issues: Chapter 1 — Understanding Disability
by Emyle Watkins • March 7, 2023
gijn.org

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THE CARTER CENTER
Mental Health Fellowship
Newsroom Collaborative
Resources
News & Updates
Contact Us
Mental Health Parity Newsroom Collaborative
The Mental Health Parity Newsroom Collaborative is a partnership between The Carter Center and news outlets in Arizona, California, Colorado, Connecticut, Georgia, Idaho, Illinois, Mississippi, Montana, New Mexico, Oregon, Oklahoma, Pennsylvania, Tennessee, Texas, Washington, West Virginia, and Washington, D.C. To date, 45 newsrooms and 150 journalists have participated, producing wide-reaching stories on mental health care access and inequities in the U.S.
mentalhealthjournalism.org/parity-collaborative/

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Media dis&dat
BA Haller's book
Locations of visitors to Media dis&dat
Media & Disability Links
Friday, April 10, 2026
The Global Disability News Network by and for disabled people launches in early 2026
media-dis-n-dat.blogspot.com

33

Key sources

- Disability rights groups. By federal law, every state has an organization that is supposed to protect and advocate for the rights of people with disabilities. Examples: www.disabilityrightsca.org/ and www.equipforequality.org/
- Peer advocates (Example: www.semel.ucla.edu/tarjan/team/kecia-weller)
- Experts in disability studies programs at universities
- People with disabilities

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Questions?

Link to slides: bit.ly/jaldis26
jlafleur@berkeley.edu

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STETSON LAW

Pooled Trusts Intensive

October 21, 2026

Technology, Choice, and Independence: The Promise and Perils of AI for People with Disabilities

STETSON LAW

Center for Elder Justice

Access and Justice For All®

SPECIAL NEEDS TRUST CONFERENCE

Technology, Choice, and Independence

The Promise and Perils of AI for People with Disabilities

Maitreya Shah
Director of Technology Policy
American Association of People with Disabilities
mshah@aapd.com

1

OVERVIEW

What We'll Cover

1	2	3	4
Opportunities	**Risks**	**Recommendations**	**Discussion**
How AI and smart technology can expand independence, agency, and privacy	Bias, inaccurate outputs, and exaggerated claims	Five practical steps for trustees, attorneys, nonprofits, and families	Your experiences with technology, and your questions

2

2

OPPORTUNITY

Emerging Opportunities: AI and Algorithmic Technology

Many new technologies open pathways to independence, agency, and privacy

1	2	3	4
Reduce reliance on human caregivers	**Enhance privacy for sensitive personal tasks**	**Make activities such as reading, writing, and communicating more accessible**	**Support more informed decision-making**

3

3

OPPORTUNITY

Image Description and Visual Interpretation Tools

ON-DEMAND VISUAL INTERPRETERS

Aira and Be My Eyes

- Help with navigating unfamiliar places
- Assist with reading mail, restaurant menus, and other materials

AI IMAGE-DESCRIPTION TOOLS

Seeing AI, Be My AI, and Aira AI

- Provide access to sensitive documents, such as medical records, without requiring human support
- Describe images on a phone or in one's surroundings

DISCUSSION PROMPT

Have you received a request from a beneficiary to pay for these services?

4

4

OPPORTUNITY

Voice Recognition and Typing Assistants

1

People with disabilities use voice recognition tools to dictate emails and messages, or to issue commands

- Examples: Speechify, Google Live, and generative AI tools such as ChatGPT

2

These tools can transform communication for people with learning or speech disabilities

- Example: Voiceitt, an AI tool that recognizes non-normative speech patterns
- Translates speech into written text and assists in online meetings

5

5

OPPORTUNITY

AI-Powered Captioning and Interpretation

Deaf people are increasingly using AI-powered captioning tools to communicate virtually

- Examples: Zoom's captioning feature, RogerVoice, and Otter.ai
- Valuable when human interpreters or captioners are not available

Some apps also offer live translation of speech into sign language

DID YOU KNOW?

The FDA approved certain Apple AirPods models, together with their companion software, as over-the-counter (OTC) clinical-grade hearing aids.

6

6

OPPORTUNITY

Smart Home Devices, Voice Assistants, and Wearable Tech

Voice assistants operate lights, thermostats, and security systems

- Increased independence for people with mobility- or dexterity-related disabilities
- Supports moving independently, cooking, cleaning, and doing laundry

EXAMPLES

Amazon Alexa-enabled devices; Google and Apple voice assistants; and smart appliances such as instant pots, microwaves, and robot vacuums

7

7

OPPORTUNITY

Technology Can Help When Human Support Isn't Available

Qualified human readers, interpreters, and captioners are hard to find

- Fewer professionals work in this field today

Government support is shrinking

- Ongoing attacks on Medicare and Medicaid
- Growing use of algorithms to reduce caregiving hours for disabled people

I personally use AI tools to read my mail, sort paperwork, and fill out medical forms

AI and smart technology cannot replace human caregivers — but they can help fill the gaps when support is unavailable

Living in our homes and communities remains paramount

8

8

OPPORTUNITY

Enhancing Privacy, Independence, and Agency

Agency	Reading medical records, communicating with doctors, and ordering prescriptions
Privacy	Blind individuals have used Aira for personal tasks, such as reading a pregnancy test
Communication	Staying in touch with family members and friends
Fitness	Tracking glucose levels, heart rate, or blood oxygen
Finance	Tracking spending and budgets

9

9

RISK

Technology Also Comes with Risks, Threats, and Lies

Google it today:

"AI and disability"

You'll see many bold claims about how technology is transforming lives

Very little conversation about bias, discrimination, and risk

AI and algorithms are trained on biased datasets, and can violate privacy or harm people with disabilities

10

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INFERENCE

Can AI Infer Disability Status from an Image?



BE MY AI

"The image shows a man standing indoors in front of a closed door … To his left, leaning against the wall, is a white cane with a red bottom, indicating he might be visually impaired."

Unprompted, the AI volunteered a disability inference nobody asked for.

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INFERENCE

Race Is a Complex Identity. Disability, Apparently, Is Not.



SAME MODEL, SAME PHOTO

- Asked to describe the photo, it volunteered: "a white cane … indicating he might be visually impaired."
- Asked directly, "What is his race?", it declined: "Race is a complex and multifaceted aspect of identity that cannot be reliably inferred from a photograph alone."

12

12

RISK

AI Is Neither Perfect nor Neutral

1

These tools are often trained on biased disability data — or no data at all

– Example: a recent CDT study found that generative AI tools such as ChatGPT and Gemini provide false information about voting accessibility

2

AI-powered tools are beneficial, but they have real limitations

– Example: image-description tools often give inaccurate details for expiry dates, medicine names, or cooking instructions

3

AI tools have also been found to discriminate against disabled job candidates, students, and benefits applicants

13

13

RISK

Beware of Exaggerated Claims

Many untested and problematic "assistive" technologies are flooding the market, often sold with bold, exaggerated claims

EXAMPLE

AI tools that claim to diagnose and "fix" disabilities like autism

Not designed with autistic people, and end up harming them

EXAMPLE

Smart glasses that claim to solve every problem for blind users

Useful for hands-free access to tools like Aira, but not the revolutionary fix they claim to be

EXAMPLE

AI companions and bots that claim to replace caregivers

These can manipulate emotions, collect sensitive information, and lead to catastrophic consequences

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RECOMMENDATION 1

Trust Technologies Backed by Evidence

1

Applicable to disabled individuals, families, nonprofits, SNTs, and attorneys

Some companies have claimed to build robots that could replace service animals

– Convincing videos, images, and marketing materials
– Advance payments of $2,000–$4,000 collected
– Buyers waited years without receiving a product

Don't fall into such traps. Do your research. Consult an expert who understands both technology and disability.

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15

RECOMMENDATION 2

Follow Emerging Trends and Regulatory Change

2

Applicable to trustees, attorneys, and nonprofits

Many states are expanding the assistive technology covered under vocational rehabilitation programs

– Example: New York City provides Meta Ray-Ban glasses as assistive technology

Check whether other programs, or assistive-technology funds, could cover some or all of the cost

Track regulatory activity from agencies such as the FCC, FDA, and FTC, as well as state and local governments

– Example: several states are restricting the use of generative AI in therapy or mental-health settings

16

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RECOMMENDATION 3

Maintain a List of Beneficial Technologies

3

Particularly relevant for pooled trusts serving beneficiaries with diverse disabilities

Track technologies that are good, legitimate, and trusted

Maintain a list of available technologies, along with vendor information

Document their uses, benefits, and risks

BENEFITS

Minimizes administrative burden, saves time and money, and improves efficiency

Consult an expert to support better decisions

17

17

RECOMMENDATION 4

Account for Technology in Annual Budgets

4

Applicable to SNTs, pooled trusts, financial advisors, and compliance professionals

AI and emerging technologies designed with disabled people can improve beneficiaries' quality of life

As technology becomes more central to daily life, demand from disabled people will keep growing

Plan ahead. Build these expenses into budgets.

Document the need for these technologies and their uses to support agency reporting

18

18

RECOMMENDATION 5

Evaluate Technology Critically. Choose Deliberately.

5

Most important for disabled individuals and their families

Don't automatically trust technology you see promoted on social media or elsewhere	**Ask around. Read up. Follow the work of organizations such as AAPD and AFB.**
Remember: technology is built by people, and it often carries their biases and prejudices	**Make an informed choice. If you are comfortable with the risks, go ahead.**

19

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DISCUSSION

Questions for the Audience

- If you are an SNT trustee or a nonprofit managing pooled trusts: have you received a request for an AI tool or assistive technology recently? What did you do?
- If you are a disabled person or a family member: have you encountered a technology you found genuinely helpful?
- Everyone else: how has technology intersected with your work?

Maitreya Shah · mshah@aapd.com · American Association of People with Disabilities

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October 21, 2026

My Cloudy Crystal Ball

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2026 National Conference on Special Needs Planning and Special Needs Trusts

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October 21-23, 2026

My Cloudy Crystal Ball:

Planning for Special Needs Beneficiaries Throughout Their Lifetime in an Era of Change

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VIII. Designing an Adaptive System Page 15

IX. Advocacy Page 18

X. Ethical and Professional Considerations Page 20

XI. Conclusion: Process Over Prediction Page 21

I. Introduction

The enactment of the “One Big Beautiful Bill Act” (HR 1) has renewed concern among families, advocates, and professionals engaged in long-term planning for individuals with disabilities. In particular, it has raised questions about the durability of public benefits, the stability of service delivery systems, and the continued viability of estate plans and special needs trusts (SNTs) built on assumptions that may not hold over a beneficiary’s lifetime. The central planning challenge, therefore, is whether the plan has been designed as a system capable of making ongoing incremental adjustments while also withstanding the inevitable shifts in public policy, funding, and administration that occur over a beneficiary’s lifetime.

Imagine that today we are planning for Kathy, a seventeen-year-old woman with a significant developmental disability. Kathy is physically healthy, but she is likely to need some degree of supervision, decision-making support, advocacy, and coordinated services throughout her life. Her parents do careful planning and establish a fully funded third-party SNT to enhance her quality of life while preserving access to public benefits when appropriate.

Then imagine that, shortly after the plan is completed, Kathy's parents pass away. The trust becomes irrevocable and enters active administration. The trustee may now be administering a system for most of Kathy's adult life. The Social Security Administration's 2023 period life table, used in the 2026 Trustees Report, gives a seventeen-year-old female an average remaining life expectancy of approximately sixty-

four years.[1] The number is not a prediction of Kathy's life; it is a planning warning. A trust that begins administration when a beneficiary is young may still be operating in the 2080s or 2090s.

Over that horizon, virtually every assumption made at the drafting table will change. Public benefits will change. Service systems will expand and contract. Housing models, health care, technology, trustees, advisors, providers, and family involvement will change. Kathy's own preferences, abilities, relationships, and support needs will also evolve.

The important point is not that the future will necessarily be worse. It may be better in ways we cannot yet imagine. Assistive technology, communication tools, transportation, housing models, medical advances, self-direction, and employment opportunities may increase independence. Flexibility is needed not only to survive disruption, but also to capture opportunity.

> ***The goal is not to predict the future. The goal is to build a plan that can adapt when our predictions are wrong.***

While HR 1 offers a contemporary illustration of this dynamic, it is not the thesis of this paper. Public policy changes repeatedly. By examining these patterns, planners can better anticipate the types of disruptions SNT beneficiaries are likely to face. The

[1] Social Security Administration, Actuarial Life Table, Period Life Table 2023, as used in the 2026 Trustees Report, https://www.ssa.gov/OACT/STATS/table4c6.html (female age 17: 63.84 years remaining life expectancy).

durable question is whether the plan has enough discretion, governance, information, advocacy, and periodic review to respond when the surrounding system changes.

One key point to remember is that every person with a disability is a unique individual. Kathy's example isn't meant to imply that all planning scenarios are the same, or even similar. Instead, special needs planning should always be customized to fit each individual, considering factors like diagnosis, family dynamics, resources, and personal goals—all of which can vary widely. Kathy's story highlights an important idea - when planning needs to span an entire lifetime, it's crucial that the plan is flexible enough to accommodate change. Flexibility, clear processes, and good governance aren't just nice-to-haves—they are vital for effective special needs trust planning.

II. Defining the Planning Horizon

Before examining why planning must anticipate change, planners should define the period and purpose for which the plan is intended to operate. Too often, the unspoken administration strategy is simply to spend the trust until it runs out. A better approach begins by identifying the trust's intended role in the beneficiary's life and aligning drafting, funding, governance, and administration with that purpose.

Kathy may require supervision, decision-making support, and coordinated services throughout her life. Because she is physically healthy, her trust may need to function for sixty years or more. Other beneficiaries may have much shorter planning horizons or a period of intensive support followed by greater independence. The point is not to force every plan into a lifetime model. Rather, it is to make the intended trajectory explicit.

A trust may be designed to fund education, vocational training, supported employment, housing, or a defined transition toward greater independence. Where family resources are limited, it may be appropriate to spend strategically on services that increase self-reliance and long-term stability rather than attempt to replace a lifetime of public or family support.

The fundamental planning error is failing to define the trust's intended trajectory: its objectives, its role in the beneficiary's life, and the degree to which it must adapt over time. Attorneys and advisors should clarify not only how long the plan may operate, but what the plan is supposed to accomplish.

III. Planning Must Assume Change

Once the design direction is established, the next step is recognizing that change is not an exception to be managed but a constant to be anticipated. Planning that assumes stability in laws, services, or family involvement may work in the short term but is fragile when assessed over the lifetime of a person with a disability.

For a beneficiary like Kathy, change will occur across several dimensions at once. Public-benefit rules may be amended, reinterpreted, or administratively revised. Service systems may expand or contract in response to funding priorities and workforce challenges. Medical advances and aging may alter functional capacity and support needs. The informal advocacy network that initially supports the beneficiary will change as parents and family members age, relocate, or pass away.

The plan therefore needs process, not prophecy. Fiduciaries should be able to assess circumstances as they exist at a given time, document their reasoning, adjust distributions and services, and remain anchored to the beneficiary's goals even when the tools available to achieve those goals are different from those anticipated at the drafting table.

IV. Looking Back: Seventy Years of Disability Policy

If Kathy may live another sixty or seventy years, one way to think about the changes she may encounter is to look back over the last sixty or seventy years. The history of disability services shows just how much can change within a single lifetime: institutions can rise and fall, federal priorities can shift, community systems can expand or contract, and new rights and service models can emerge. History cannot predict the future, but it can help us understand the kinds of change a long-term plan must be prepared to absorb.

A. Institutional Origins and Early Reform

In the nineteenth and early twentieth centuries, reformers advocated for public institutions as alternatives to jails, poorhouses, and almshouses for people with mental illness and developmental disabilities. Many institutions were created with sincere aspirations of safety, schooling, medical supervision, structure, work, recreation, and protection. Yet those systems depended on sustained funding, adequate staffing, manageable populations, and meaningful oversight.

As admissions increased and resources failed to keep pace, many institutions became overcrowded and understaffed. Therapeutic aspirations gave way to

custodial care. Burton Blatt and Fred Kaplan's 1966 photographic essay, Christmas in Purgatory, became one of the most influential depictions of institutional conditions during this era. [2][2] The planning lesson is not that reformers lacked compassion. It is that a service model can begin with humane intentions and still deteriorate when its operating conditions change.

B. Deinstitutionalization and Federal Expansion

By the middle of the twentieth century, investigative reporting, litigation, family advocacy, disability-rights organizing, and broader civil-rights movements prompted a reassessment of institutional care. The federal legislation commonly associated with the Community Mental Health Act of 1963 authorized grants for community mental-health centers, while the Mental Health Systems Act of 1980 later sought a broader federal role in planning and supporting community mental-health services.[3,4]

The aspiration was that people should not be unnecessarily confined and that meaningful supports should exist in the community. But community-based systems required persistent funding, workforce development, administrative capacity, housing, crisis services, and political support. Closing an institution can be measured. Building a durable community infrastructure over decades is harder.

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[2] Burton Blatt & Fred Kaplan, Christmas in Purgatory: A Photographic Essay on Mental Retardation (1966).

[3] Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963, Pub. L. No. 88-164, 77 Stat. 282 (1963), including Title II concerning community mental health centers.

[4] Mental Health Systems Act, Pub. L. No. 96-398, 94 Stat. 1564 (1980).

C. The 1981 Retrenchment

The Omnibus Budget Reconciliation Act of 1981 marked an important turn in federal mental-health policy. It repealed major portions of the Mental Health Systems Act and shifted funding toward block grants and greater state discretion.[5] It did not affect every disability program in the same way, and it should not be treated as a single explanation for the later condition of community services. It nevertheless illustrates a recurring planning reality: financing structures and governmental responsibility can change even while the underlying need for services remains or grows.

For special needs planners, the historical point is straightforward. A benefit or service structure that appears established today cannot be assumed to operate in the same form decades from now. State choices, waiver design, appropriations, provider markets, and administrative capacity can materially affect what an eligible person actually receives.

The comparison to current federal policy is not that H.R. 1 repeats OBRA 1981 or converts Medicaid into a block-grant program. Rather, OBRA 1981 illustrates how changes in federal financing and federal-state responsibility can reshape service systems over time, often in ways that are difficult to foresee when legislation is enacted. That historical lesson provides useful context for evaluating H.R. 1 and other future policy changes over a beneficiary's lifetime.

[5] Omnibus Budget Reconciliation Act of 1981, Pub. L. No. 97-35, 95 Stat. 357 (1981).

D. A Mature System Can Still Change: California Mental Health

In California, the Short-Doyle Act of 1957 supported locally administered community mental-health programs years before the later federal initiatives. Over time, state financing formulas, deinstitutionalization, Medi-Cal, and fiscal realignment repeatedly changed how the system was organized and funded.[6]

Here, it is clear that even a mature community system can retain important strengths while its financing, administration, local capacity, and service mix continue to evolve. For a long-term planner, the relevant question is not whether a program survives in name. It is whether the beneficiary can obtain the needed support when the need arises.

V. Community Living

Community systems can fail in different ways: too few waiver slots; inadequate crisis services or supported housing; weak transition planning; insufficient workforce capacity; poor quality oversight after a service is authorized; fragmented state and local administration; or long delays between eligibility and actual service delivery.

A. Texas: Interest Lists and Capacity-Limited Supports

Texas programs illustrate the planning risks created by capacity-limited systems. Texas maintains interest lists for multiple long-term services and supports waiver programs, including Home and Community-based Services and Texas Home

[6] California Legislative Analyst's Office, Major Milestones: 43 Years of Care and Treatment of the Mentally Ill (2000), https://lao.ca.gov/2000/030200_mental_illness/030200_mental_illness.pdf.

Living.[7] Placement on an interest list is not the same as enrollment, and services depend on program rules, available capacity, and an eventual offer.

Texas also continues to operate State Supported Living Centers. In 2009, the U.S. Department of Justice and Texas entered into a settlement addressing conditions and practices at thirteen state facilities, including protection from harm, behavioral and mental-health services, health care, discharge planning, and support for integrated placement.[8] While these efforts produced measurable operational improvements, they did not alter the underlying structural reality: Texas' system continues to depend heavily on discretionary funding, constrained program capacity, and administratively complex service delivery.The example shows that a state may simultaneously maintain institutional capacity and community programs while still confronting substantial questions of access, quality, and transition.

B. Different States, Different Failure Modes

Virginia demonstrates another pattern. A 2012 federal settlement was designed both to expand community services for people with intellectual and developmental disabilities leaving institutions and to reduce the risk of unnecessary institutionalization for people living in the community, including people waiting for waiver services. The agreement required thousands of new home- and community-

[7] Texas Health and Human Services, Community Services Interest List, Revision 26-2 (effective June 1, 2026), https://fhb.hhs.texas.gov/handbooks/star-kids-program-support-unit-operational-procedures-handbook/1500-psu-online-database-resources.

[8] U.S. Department of Justice, Justice Department Files Complaint and Reaches Settlement to Improve Conditions at Texas State Facilities for Persons with Developmental Disabilities (June 26, 2009), https://www.justice.gov/archives/opa/pr/justice-department-files-complaint-and-reaches-settlement-improve-conditions-texas-state.

based waiver opportunities, family supports, crisis services, housing assistance, supported employment, and quality oversight.[9]

New Hampshire's mental-health settlement illustrates a different set of gaps: statewide Assertive Community Treatment, supported housing, mobile crisis services, and other community supports were central to the remedy.[10] These examples do not prove that community living is unrealistic or that every state system is failing. They demonstrate that community living depends on durable capacity, and the weak point differs by jurisdiction. Additionally, most state programs' demand has consistently exceeded available waiver slots, resulting in wait times that often extend for many years. For families, placement on a waiting list offers limited predictability regarding when, if ever, meaningful support will become available.

As such, for trustees and planners, geography may be a planning variable. A trust created in one state may later be administered for a beneficiary living in another. Eligibility does not always mean timely service availability. A move may alter waiver access, provider networks, housing opportunities, transportation, state supplementation, care-management options, and the beneficiary's informal support network.

When service systems are contingent rather than guaranteed, families cannot assume continuity, adequacy, or timeliness of public support. Effective special needs planning must therefore account not only for eligibility rules, but also for service

[9] U.S. Department of Justice, United States v. Commonwealth of Virginia, Settlement Agreement and Fact Sheet (2012), https://www.justice.gov/crt/united-states-v-commonwealth-virginia.
[10] U.S. Department of Justice, New Hampshire ADA Mental Health Settlement Fact Sheet, https://www.justice.gov/crt/about/spl/documents/nhada_factsheet.pdf.

delays, workforce instability, geographic disparities, and the likelihood that private resources may be required to bridge gaps for extended periods. These issues underscore why SNTs must be capable of supplementing—and, when necessary, temporarily replacing—public services in order to preserve a beneficiary's quality of life over time.

VI. H.R. 1 in Historical Context

H.R. 1 should be understood as a contemporary illustration of system change, not as an unprecedented event or a prediction that every person with a disability will lose benefits. The law does not eliminate Medicaid, and important exclusions apply to many people with disabilities and caregivers. For beneficiaries with intellectual, developmental, or psychiatric disabilities, the primary risk posed by H.R. 1 is often not substantive ineligibility but procedural failure. Increased reporting obligations, shortened eligibility windows, and heightened verification requirements disproportionately affect individuals who rely on representative payees, family members, or service providers to navigate complex administrative processes. Even temporary lapses in compliance can result in benefit suspension, service disruption, or the loss of provider relationships.

CMS's June 2026 interim final rule explains that the new Medicaid community-engagement requirement generally applies to specified non-pregnant adults ages nineteen through sixty-four who are eligible for the Medicaid adult group or certain comparable demonstration coverage, and the rule recognizes statutory exclusions and

exceptions.[11] It would therefore be inaccurate to assume that the requirement applies to every Medicaid beneficiary with a disability.

The larger planning lesson is administrative. Changes in eligibility procedures, reporting, renewal, financing, or coverage rules can create friction even when the core program continues. New forms, deadlines, verification systems, agency guidance, and state implementation choices can produce delay and uncertainty. In a capacity-limited system, administrative disruption can compound an existing service gap.

The professional response should not be fear-based drafting around one statute. It should be a governance structure that can recognize a change, obtain current advice, reassess available public and private supports, and authorize an appropriate response. The objective is not to predict the next policy shift but to ensure that the plan remains functional and responsive when it occurs.

VII. Why Static Special Needs Planning Is Fragile

Much special-needs planning remains implicitly static. Trusts may be drafted with careful attention to current eligibility rules and technical compliance but sometimes pay insufficient attention to how those provisions will function when circumstances inevitably change.

Static planning overvalues present-day benefit structures. It also underestimates human turnover. Trustees, advisors, care providers, and family advocates will change. Without

[11] Centers for Medicare & Medicaid Services, Medicaid Community Engagement Requirement for Certain Individuals Interim Final Rule with Comment Period (CMS-2454-IFC), Fact Sheet (June 1, 2026), https://www.cms.gov/newsroom/fact-sheets/medicaid-community-engagement-requirement-certain-individuals-interim-final-rule-comment-period-cms.

mechanisms to preserve institutional knowledge, guide successor fiduciaries, and recalibrate decision-making, administration can become reactive rather than intentional.

Static design also underestimates cumulative change. A modest service reduction, a new administrative requirement, a housing problem, a provider closure, or a temporary gap may each appear manageable in isolation. Across decades, small changes compound. Drafting that was technically elegant at inception can become poorly matched to the beneficiary's actual life.

> ***A long-term plan should be designed to remain useful after the assumptions that produced it are no longer true.***

VIII. Designing an Adaptive System

Although these principles inform many forms of special-needs planning, the examples here primarily assume a third-party SNT. First-party trusts, pooled trusts, and settlement-funded trusts can involve additional statutory, reimbursement, tax, and fiduciary considerations.

The solution is not merely broader drafting language. The trust instrument is indispensable, but it is only one component of the plan. The operative plan is a system of people, information, governance, advocacy, financial resources, monitoring, and reassessment. For beneficiaries whose needs may extend across decades, a trust should provide a framework for ongoing decision-making rather than a fixed set of instructions tied to present conditions.

At the core of this approach is recognition that no drafting attorney, trustee, or family can accurately predict the beneficiary’s future needs, the availability of public services,

or the legal and administrative environment in which the trust will operate. Effective design therefore emphasizes process over prediction. The trust must empower fiduciaries to assess circumstances as they exist at any given point in time and to respond deliberately as those circumstances change.

A. Why Institutional Continuity Matters: The Pooled Special Needs Trust Example

Pooled Special Needs Trusts ("PSNTs") illustrate one way to build continuity into long-term administration. Federal law permits a qualifying PSNT to maintain separate beneficiary accounts while pooling funds for investment and management purposes, with the trust established and managed by a nonprofit association.[12] That structure can provide continuity beyond any one parent, sibling, trustee, advisor, or service provider.

A pooled trust does not eliminate uncertainty, and pooled trusts are not interchangeable. The master trust, joinder agreement, distribution policy, investment policy, administrative systems, and applicable state Medicaid rules all matter. Institutional continuity can reduce the risk that a beneficiary is left without knowledgeable administration when family advocates are no longer available.

B. Process-Based Administration and an Annual Distribution Plan

A practical way to implement flexibility is a recurring planning process, often embodied in an annual distribution plan. Rather than treating distributions as a

[12] 42 U.S.C. § 1396p(d)(4)(C); see also Social Security Administration, POMS SI 01120.203 (pooled trust requirements).

series of ad hoc approvals, the annual plan identifies anticipated needs, evaluates available public benefits and services, establishes priorities for trust expenditures, and documents the reasoning behind major tradeoffs.

For Kathy, the process should incorporate input from the trustee, legal and financial advisors, care managers, and, to the greatest extent practicable, Kathy herself. The objective is not merely to budget funds. It is to create a shared picture of goals, risks, resources, and responsibilities and to revisit that picture as circumstances change.

C. Governance, Oversight, and Continuity

Flexibility must be paired with accountability. Over a long planning horizon, trustee turnover is inevitable and institutional knowledge can be lost. Governance structures such as advisory committees, trust protectors, designated successor fiduciaries, and documented decision-making protocols can preserve intent and provide checks and balances.

The drafting question is not simply who should serve today. It is how the system will select, monitor, replace, and educate the people who will serve later.

D. Funding, Sustainability, and Tradeoffs

Adaptability requires an honest assessment of funding. Trustees must balance current quality-of-life expenditures with the need to preserve resources for later stages of life, including periods of increased health, housing, or support needs. Inflation and rising labor and housing costs make the analysis more difficult.

Where resources are limited, the plan may need to prioritize expenditures that increase long-term independence or prevent larger future costs. A technically correct

distribution plan is not enough; fiduciaries need a method for deciding among competing good uses of a finite fund.

E. Flexibility With Public Benefits

Public benefits are tools, not the ultimate objective. A trust designed for adaptability should be able to supplement—and, when appropriate and legally permissible, temporarily replace—public services when delay, disruption, or administrative failure would otherwise jeopardize the beneficiary's safety, housing, dignity, autonomy, or quality of life. Preserving eligibility can be important, but eligibility should not become an end in itself.

IX. Advocacy

Parents often become highly skilled advocates through years of interactions with schools, service providers, medical systems, and benefit agencies. They learn the beneficiary's history, communication style, warning signs, preferences, tolerances, relationships, and the practical difference between a service that is authorized on paper and a service that actually works.

When a parent dies or can no longer serve, the assets may transfer neatly into a trust. The advocacy does not. That function must be intentionally transferred through people, records, relationships, governance, and recurring review.

A trustee should have a process for recognizing when the beneficiary's informal advocacy network has weakened. At that point, the plan may need to fund care management, independent monitoring, advocacy support, supported decision-making

assistance, or other protective services. The annual distribution plan is a natural place to ask whether the beneficiary's living situation, providers, health, relationships, safety, and goals still align with the plan.

By embedding advocacy and oversight in the trust's ongoing process, planners can reduce the risk that a beneficiary becomes isolated or underserved as family involvement diminishes over time. This approach reflects a realistic understanding of long-term administration: safeguarding quality of life over an actuarial lifespan requires vigilance, coordination, and a structure that treats advocacy as a core trust function rather than an optional add-on. A practical solution to addressing advocacy may look like the following:

Practical Planning Matrix

Planning issue	Adaptive design response team
Change in public benefits or services	Trustee or pooled-trust administrator discretion to supplement or temporarily replace supports; periodic reassessment of available benefits and services.
Parent or sibling can no longer advocate	Care-manager role, advisory committee, designated advocates, and documented beneficiary preferences, history, and communication needs.
Trustee turnover or administrator succession	Successor-fiduciary process, organized records, written annual plans, and a governance mechanism capable of replacing a poorly performing fiduciary.
Service or provider failure	Authority to change providers, fund interim supports, and obtain independent assessment or care management.
Change in beneficiary needs or preferences	Recurring review that includes the beneficiary to the greatest extent practicable and revisits goals rather than merely prior spending patterns.
Geographic move	Reassess state-specific benefit rules, waiver or interest-list access, providers, housing, and the local support network.
Funding pressure	Multi-year cash-flow review, reserves where appropriate, and an explicit process for prioritizing quality-of-life expenditures.

Of note, this Practical Planning Martix is intentionally process-focused. It does not attempt to predict which benefit program, provider, or family member will be present in a particular year. It identifies recurring categories of change and pairs them with a structure capable of responding.

Taken together, these design principles reflect a fundamental shift in perspective: when planning for the actuarial life of a beneficiary, flexibility and governance are not optional features but essential components of competent SNT planning.

X. Ethical and Professional Considerations

Periods of policy volatility heighten the professional demands on attorneys, trustees, and advisors. Competent representation requires more than technical compliance with current law; it also requires careful counseling about long-term risk, tradeoffs, and the limits of predictability. The ABA Model Rules frame competence in terms of legal knowledge, skill, thoroughness, and preparation, and require lawyers to explain matters sufficiently for clients to make informed decisions.[13]

One ethical challenge is fear-based planning. Legislative change and media coverage can create pressure to draft around the latest perceived threat or to promise certainty where none exists. Overreaction can be as harmful as complacency when it produces rigid provisions that constrain future fiduciaries.

[13] ABA Model Rules of Professional Conduct, Rules 1.1 (Competence) and 1.4 (Communication), https://www.americanbar.org/groups/professional_responsibility/publications/model_rules_of_professional_conduct/.

Families should also understand that preserving eligibility for a public benefit may at times conflict with other objectives, including safety, autonomy, housing stability, or quality of life. Advising a client that private resources may someday need to bridge a service gap is not pessimism. It is part of candid long-term counseling.

Ethical practice also requires humility. No planner can predict future legislation, service systems, technology, family circumstances, or social conditions with precision. The professional answer to uncertainty is not certainty; it is thoughtful design, clear communication, documentation, and a process that can adapt.

XI. Conclusion: Process Over Prediction

Kathy's story illustrates the central challenge of modern special-needs planning. A trust that becomes irrevocable when she is seventeen may operate for six or seven decades. Over that period, public benefits will evolve, service systems will expand and contract, fiduciaries will turn over, technology may create new opportunities, and Kathy's own needs and preferences will change in ways that cannot be fully anticipated at the outset.

The historical record—from institutional care, to deinstitutionalization, to changing federal and state financing, to state-by-state variation in community capacity—shows that instability is not an anomaly. Change is a recurring feature of disability-service systems. But change should not be equated with decline. Future systems may offer supports, technologies, housing models, and forms of independence that are better than anything available today.

For attorneys, trustees, and advisors, the task is therefore not to draft a document optimized only for current conditions. It is to design a system that can function as

conditions change: a trust with sufficient discretion; people who can exercise that discretion intelligently; information that survives family turnover; governance that creates accountability; advocacy that does not disappear with the parents; and a recurring process for reassessing the beneficiary's actual life.

Effective special-needs planning is ultimately measured not by technical compliance at inception, but by whether the plan continues to safeguard dignity, safety, autonomy, relationships, and quality of life decades later. Planning for change is not an exercise in pessimism. It is a recognition of reality—and an opportunity to build a plan resilient enough to benefit from a future we cannot yet see.

The views and opinions expressed in this paper are solely those of the authors and do not necessarily reflect the views of True Link Financial Advisors, LLC.

STETSON UNIVERSITY

2026 National Conference on Special Needs Planning and Special Needs Trusts

My Cloudy Crystal Ball

Planning for Special Needs Beneficiaries Throughout Their Lifetime in an Era of Change

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One Big Beautiful Bill Act of 2025 (H.R. 1)

- Introduced sweeping changes to Medicaid
  - Work requirements (mainly ACA Medicaid)
- More frequent eligibility checks
- Less retroactive coverage
- Large federal funding cuts and new state limits
  - Projected $793B to $1.02T in cuts over next ten years
- Narrower immigrant eligibility
- Potential losses for dual-eligible beneficiaries

2

2



Change Is Inevitable

- Benefit laws ~~may~~ will change
- Social service systems will change
- Housing models, health care, technology, etc. will change
- Trustees and advisors and advocates will change
- Kathy's condition may change
- Kathy's preferences, needs, abilities and relationships will change
- State and federal administration attitudes may change
- The amount of resources Kathy needs may change

The goal is not to predict the future. The goal is to build a plan that can adapt when initial predictions are incorrect.

3

3



Kathy

- 17 years old, significant developmental disability
- Physically healthy - could live into her 70s
  - Trust may be operating into the 2080s
- Will need decision-making support, advocacy, and coordinated services for decades
- Social service systems will change
- Her condition may change
- Her advocacy system may change
- Attitudes may change
- The amount of resources she needs may change
- A 17 year old today may live into the 2090s

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4

Looking Back: 70 Years of Disability Policy

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19th- and early 20th- century origins

In the mid-1800s, social reformers advocated for the creation of public hospitals for people with mental illness and developmental disabilities.

The idea was to provide a **humane alternative** to jails and almshouses, where many people with mental illness were previously confined.

States built large institutions on rural campuses — these were often self-contained communities, including farms, workshops, and living quarters.

6

6

Results

- Reliance on:
  - sustained funding
  - adequate staffing
  - manageable populations
  - meaningful oversight
- Admissions increased
- Resources failed to keep pace
- Overcrowding
- Understaffed
- Therapeutic aspirations -> custodial care

Reformers didn't lack compassion - service model deteriorated when operating conditions changed.



Burton Blatt & Fred Kaplan, Christmas in Purgatory: A Photographic Essay on Mental Retardation (1966)

7

Deinstitutionalization & Federal Expansion

Community Health Act of 1963

- Brought about through advocacy from investigative reporting, family advocacy litigation and disability-rights organizations
- Signed by President Kennedy
- Shift from institutions to community care
- Federal grants to Community Mental Health Centers (CMHCs)
- Planned for 1,500 - 2,000 CMHCs nationwide - fewer than half were built
- Funded construction but not staffing
- State hospital populations dropped and many people gained more independence
- May have led to more homelessness and incarceration of people with disabilities

Mental Health Systems Act of 1980

- Brought about through the President's Commission on Mental Health (1977-78), chaired by First Lady Rosalynn Carter
- Signed by President Carter
- Aimed to fixed gaps of 1963 Act:
  - Focus on ongoing services
  - Gave states a larger role in planning and coordinating care
- Prioritized chronic, serious mental illness and underserved populations
- Recommended a "bill of rights" for people receiving mental health care
  - Confidentiality
  - Informed consent
  - Freedom from unnecessary restraint
  - Treatment in the least restrictive setting
- Largely repealed within a year

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The 1981 Retrenchment

Omnibus Budget Reconciliation Act of 1981 (OBRA '81)

- Repealed major portions of the Mental Health Systems Act of 1980
- Signed by President Reagan
- Created Medicaid Home and Community-Based Services (HCBS) waivers
- Made continued Medicaid eligibility the centerpiece of many disability plans
- Shifted funding to block grants, thus giving states more discretion
- Allowed states to disregard family income
  - Allowed states to apply institutional eligibility rules, eliminating some "deeming"
- Introduced waiting lists for services as waivers had to be cost-neutral when compared to institutional care
  - Note: impact on planning if a beneficiary moves states
- Created Medicaid "freedom of choice" waivers

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State Issues

Texas

- According to The Arc of Texas Harris County and related provider data, over 158,000 Texans with disabilities are waiting for HCBS waiver slots
- Corpus Christi State School "fight clubs"
- State Supported Living Centers (SSLCs)
  - U.S. Department of Justice and state of Texas entered into a settlement agreement in 2009 addressing conditions and practices at 13 state facilities (protection from harm, health care, discharge planning, etc.)
- System relies heavily on discretionary funding and constrained capacity

Virginia

- 2012 U.S Department of Justice vs. Virginia settlement
- DOJ concluded that VA violated the Americans with Disabilities Act by unnecessarily institutionalizing people with IDD
  - Cited insufficient community services, unreasonably long Medicaid waiting list and inadequate discharge planning
- Settlement expanded HCBS waiver slots, family support programs, and integrated employment and housing options
- VA agreed to phase out 4 of 5 "training centers" and spend $2.1B over the next decade to expand community-based care
- Case is still listed as "ongoing"

New Hampshire

- 2013 U.S Department of Justice vs. New Hampshire settlement
- DOJ concluded that NH violated the Americans with Disabilities Act by failing to provide enough community services for people with mental illness in the most integrated setting
- Settlement established the Community Mental Health Agreement
  - NH expanded Assertive Community Treatment to cover at least 1,500 people statewide
  - Added hundreds of supported housing units
  - Reformed transition planning for people leaving two state institutions
- NH received notice of noncompliance in 2021 - with a court approved plan in 2023
- Case and oversight remain ongoing

10

Adaptation Can Work

California

- Short-Doyle Act of 1957
  - Supported locally administered county community mental-health programs well before federal initiatives - initially matching funding 50/50
  - Strengthened by the Lanternman-Petris-Short Act of 1967
    - Limited involuntary commitment and pushing care into community hands
  - Faced state financing formulas, deinstitutionalization, Medi-Cal changes, administration priority shifts, etc.
    - Funding shifted to sales tax and vehicle license fees
  - Still the backbone of CA's public mental health system

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H.R. 1

- Does **not** eliminate Medicaid
  - Important exclusions apply to many people with disabilities and caregivers
- Risk = **not** substantive eligibility; rather, procedural failure
  - Increased reporting obligations
  - Shortened eligibility windows
  - Heightened verification requirements
- Temporary lapses in compliance may result in:
  - Benefit suspension
  - Service disruption
  - Loss of provider relationships
  - Wait lists
- Medicaid Community-Engagement requirement
  - CMS interim final rule (June, 2026)
    - Applies to specified non-pregnant adults (ages 19-64) eligible for Medicaid adult group or comparable coverage
    - Recognizes statutory exclusions and exceptions
    - I.e., does **not** apply to every Medicaid beneficiary with a disability

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Over the past 70 years

- Since the 1950s, the U.S. has experienced more than a dozen significant policy reforms affecting disability services,
- at least seven major economic recessions,
- multiple periods of high inflation and economic growth,
- over a dozen foreign conflicts or military operations, dramatic increase in climate-related natural disasters and
- At least 5–10 major social or global crises (pandemics, civil unrest, large-scale disasters)

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Static Special Needs Planning Is Fragile

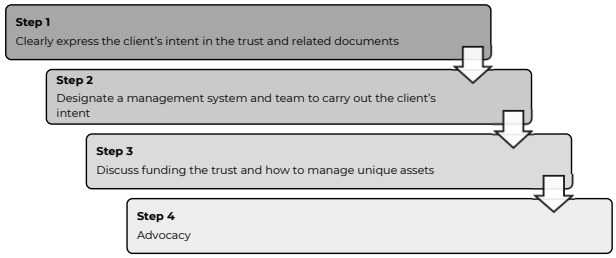
- SNTs
  - Must be drafted with careful attention to current eligibility requirements and technical compliance
    - May overvalue present-day benefit structures
    - May underestimate human turnover
      - Trustees, advisors, care providers, advocates, family
      - Needs to contemplate preservation of knowledge of beneficiary
    - May underestimate cumulative change
      - Service reductions, administrative requirements, housing issues, provider closures, benefit gaps

A long-term plan should be designed to remain useful after the assumptions that produced it are no longer valid.

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4 Step Process



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Step 1: Grantor Intent

- One of the trustee's fundamental duties is to administer the trust in accordance with the **grantor's intent**.
- A bare bones trust that only focuses on preserving eligibility for SSI and Medi-Cal will lack the proper directions needed for a trustee to carry out their duties.
- Proper documentation of the grantor's intent, will allow the trustee to understand the grantor's values and objectives
- **The SNT should have broad information** for overall guidance to the trustee and advocate.
- The letter of intent should give more detailed information.
- Think of the letter of intent as a journal of ongoing documentation of the beneficiaries needs.

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Step 2: Choice of Trustee

- Family
- Private Fiduciary
- Corporate Trustee
- Pooled Trust

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Step 2: Family and Friends as Trustee

- There is always an inclination to appoint family members as successor-trustees of Special Needs Trusts.
- Many family member trustees fail because they are not adequately prepared to navigate the complexities of benefits eligibility and the coordination of necessary services.
- This does not mean that family should not be included. This means only that they play more of a supervisory role.

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Step 2: PSNTs

Pooled Special Needs Trusts (PSNTs)

- Provides continuity beyond parents, siblings, trustees, advisors, service providers
- Robust knowledge of public benefits
- Person-centered approach
- 3rd Party standalone SNT administration
  - Successor trustee
  - Test run during settlor lifetime
  - Periodic funding
  - Spend-down/consolidation
  - Distribution advisor

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Step 2: Model

The Trustee Directed by a Trust Advisory Committee

Trustee Duties:
Manage assets, make distributions, file taxes, and maintain records.

Oversight:
Trust Advisory Committee or trust protector advises distributions, may amend terms, or replace the trustee.

Care Management:
Care manager assesses beneficiary needs and supports the management team.

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Step 2: Trust Advisory Committee

- Promotes settlor intent and beneficiary involvement
- May weigh in on discretionary distributions
- May be tasked with development of distribution plan
- Supporters may act as part of Committee
  - Best Practice: identify any conflicts of interest (e.g., remainderperson, housemate, etc.)

From Wealth Counsel:

"The Trust Advisory Committee shall consist of a minimum of 3 members, but no more than 5 members to be determined by the chairperson(s) then serving. If any member of the Trust Advisory Committee is unwilling or unable, for any reason, to act or continue to act as a committee member, the chairperson(s) then serving may decide whether or not to fill the vacancy. However, there shall be at least three (3) members serving at all times. If there are fewer than 3 members serving and the chairperson(s) then serving are unable or unwilling to appoint a successor committee member, the Trustee may appoint the successors."

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Sample Language

Distribution Advisement

The Trust Advisory Committee will advise the Trustee regarding distributions believed to be in Tommy Trojan's best interests, including, but not limited to, distributions for supportive services and major purchases as outlined in this Section. Before the Trustee distributes trust property as authorized by this agreement, the Trustee may first seek the Trust Advisory Committee's advice and recommendations, but is not required to do so, and may make a distribution without contacting or soliciting the advice of the Trust Advisory Committee. This Section in no way affects the sole and absolute discretion of the Trustee under this agreement.

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Step 2: Trust Protector

- Promotes settlor intent and beneficiary involvement
- May remove trustee
- May amend trust document for changes in law, public benefits, etc.
- May weigh in on discretionary distributions
- Supporters may act Trust Protector
  - Best Practice: identify any conflicts of interest (e.g., remainderperson, housemate, etc.)

From Bradley J. Frigon, JD, LL.M (tax), CELA, CAP:

"The Trust Protector may amend any provision of this Agreement, as it applies to any Trust for which the Trust Protector is serving, pursuant to [subsequent restrictions]. Notwithstanding the foregoing, the Trust Protector may not amend this Agreement in any manner that would make Trust corpus or income available to the Beneficiary for Medicaid eligibility. Further, the Trust Protector may not limit or alter the rights of the Beneficiary in any Trust assets held by the Trust before the amendment, nor may the Trust Protector remove or add any individual or entity as a beneficiary of any Trust asset."

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Step 3: Funding

How Much Should a Parent Set Aside for the Needs of their Child with a Disability

- "This is nearly impossible to answer — much like asking how many angels with disabilities could fit on the head of a pin."
- Even so – it may be time to rethink funding and probably dig deeper.

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Step 3: Funding

Distribution Plan/Tax

- Third-party Special Needs Trusts are treated as complex trusts under the Internal Revenue Code—making them tax-sensitive vehicles.
- A detailed distribution plan allows the attorney, CPA or tax preparer to align strategy with execution, identify deductible expenses, and structure income allocation effectively.
- The plan ensures advisors are working from the same set of priorities, timelines, and financial realities.

The tax advisor can:

- Optimize income distribution between trust and beneficiary
- Leverage deductions (e.g., care management, medical costs)
- Reduce tax drag over time
- Third-party SNTs operate similarly to bypass trusts:
  - they accumulate income,
  - face compressed tax brackets, and
  - require strategic income management.
- The distribution plan makes that strategy possible.

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Step 3: Funding

Distribution Plan/Financial Advisor

- Annual Distribution Planning: The trust required yearly reviews of living needs, health care, and long-term financial sustainability.
- Actuarial Projections: Financial advisors used actuarial modeling to assess whether trust assets could support projected distributions over time.
- Fiduciary Discipline: Projections guided the trustee and management team, preventing overextension and supporting prudent, budget-like decision-making.
- Aligned Investment Strategy: A clear distribution plan enabled asset allocation to be structured around real-world needs rather than guesswork.

The Distribution Plan and Sustainable Services

- The distribution plan also serves a critical role in determining which services are appropriate and sustainable for someone like Kathy.
- During planning discussions, it is not unusual to identify potential distributions that may be beneficial in theory—such as private housing upgrades, intensive therapies, or luxury recreational opportunities—but that may not be actuarially sound over the lifetime of the trust.
- Public benefits are a tool, not the ultimate objective.
- Plans may be dependent upon funding
- Consider prioritizing expenditures that promote long-term independence or prevent larger future costs

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Step 3: Funding (Budget)

Cost/Benefit Analysis: Identify those expenses that may be covered by public benefits. Consider 1/3rd ISM reduction

Transportation: Own vs. Lease?

Housing: Own vs. Rent?
- "Hidden" costs (insurance, utilities, taxes, maintenance, etc.)

Trust Longevity simulation:
- **TIP: adjust for inflation (not just CPE, but also food and medical)**

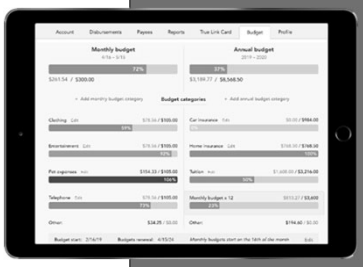
Budget for professional costs and fees

Optimal Outcomes:
- Start a business, attend college, travel, retirement
- Remainder person considerations
- **TIP: record all for future use**

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Step 3: Funding (Budget)



For illustrative purposes only.
Trust Administration Software provided by True Link Financial, Inc.

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Step 3: Funding (Qualified Plans)

Qualified Plans

A **qualified plan** is an employer-sponsored retirement plan that satisfies the requirements of the Internal Revenue Code Section 401(a) and ERISA, allowing it to receive favorable tax treatment for both employers and employees.

Examples include:

- 401(k) plans
- Defined benefit (pension) plans
- Profit-sharing plans
- Money purchase pension plans

Unique Assets

- **Real Estate**
  - Planning for Appropriate Housing can be difficult.
  - Funding the SNT with real estate pros and cons.
- **Qualified Plans**
  - Should consider the tax implications of SECURE and SECURE 2.0
  - SNT is an Eligible Designated Beneficiary

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Designing an Adaptive System

- ✔ **Design trusts to be flexible**—not just to preserve benefits, but to replace them if they disappear or the quality is unacceptable
- ✔ **Build in private care support** options: care managers, professional fiduciaries, pooled trusts, and advisors.
- ✔ **Create sustainable distribution plans** that anticipate surges in care costs and reductions in service availability.
- ✔ **Consider allocating more to the SNT** in anticipation that services may not be available or lack quality

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Step 4: Advocacy

- Long Medicaid HCBS waiver waitlists leave families providing care for years
- Many states heavily on unpaid family caregivers due to capped community services
- Caregiving responsibilities increasingly include medical and behavioral support
- Workforce shortages and service gaps intensify family strain
- Preservation of beneficiary's history, communication style, health, warning signs, preferences, relationships, etc.
- Assets transfer to a trust - advocacy does not

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Advocacy

Planning issue	Adaptive design response team
Change in public benefits or services	Trustee or pooled-trust administrator discretion to supplement or temporarily replace supports; periodic reassessment of available benefits and services.
Parent or sibling can no longer advocate	Care-manager role, advisory committee, designated advocates, and documented beneficiary preferences, history, and communication needs.
Trustee turnover or administrator succession	Successor-fiduciary process, organized records, written annual plans, and a governance mechanism capable of replacing a poorly performing fiduciary.
Service or provider failure	Authority to change providers, fund interim supports, and obtain independent assessment or care management.
Change in beneficiary needs or preferences	Recurring review that includes the beneficiary to the greatest extent practicable and revisits goals rather than merely prior spending patterns.
Geographic move	Reassess state-specific benefit rules, waiver or interest-list access, providers, housing, and the local support network.
Funding pressure	Multi-year cash-flow review, reserves where appropriate, and an explicit process for prioritizing quality-of-life expenditures.

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Step 4: Advocacy

Care Management

- In many cases, utilization of a care manager can assist in coordinating services for the beneficiary.
- Can often identify issues such as over medication, safety issues, or care giving issues.
- Some are skilled in analyzing benefits and services that may be available.

Supported Decision-Making

- Least restrictive alternative
- Person-centered planning opportunities
- Beneficiary empowerment
- Support system

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Ethical and Professional Considerations

- **Policy volatility heightens demand** for planners to counsel about long-term risk, trade-offs, limits of predictability
- **Fear based planning** creates pressure to draft around latest media coverage or perceived threats
- **Counsel should help families** understand that preservation of benefits may conflict with other objectives: safety, autonomy, housing stability, quality of life
- **Advising a family that private resources may be needed** is not pessimism - it's candid long-term planning.
- **Ethical planning must assume humility** as no planner can predict future legislation, technology, family circumstances, social conditions or beneficiary preferences and needs

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Designing an Adaptive System

- **Process over prediction**
- **Design trusts to be flexible**—not just to preserve benefits, but to replace them if they disappear or the quality is unacceptable
- **Future systems may offer** better supports, technologies, housing models, and forms of independence
- **Build in private care support** options: care managers, professional fiduciaries, pooled trusts, and advisors.
- **Create sustainable distribution plans** that anticipate surges in care costs and reductions in service availability.
- **Consider allocating more to the SNT** in anticipation that services may not be available or lack quality
- **Planning for change is not an exercise in pessimism** - it is a recognition of reality

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2026 National Conference on Special Needs Planning and Special Needs Trusts

Thank You!

My Cloudy Crystal Ball

Planning for Special Needs Beneficiaries Throughout Their Lifetime in an Era of Change

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Pooled Trusts Intensive

October 21, 2026

From Tragedy to Triumph and Everything in Between

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October 21, 2026

Technology is a Reasonable Expense

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Technology is a Reasonable Expense:

A Practical Legal Framework for Technology-Related Distributions from Special Needs and Pooled Trusts

Eric J. Einhart, Esq.

Stetson Special Needs Trust Conference • Pooled Trust Intensive

October 21, 2026

CLE Written Materials

Funding and Cost-Saving Resources

A useful conference handout should give attorneys places to send clients, not merely tell them to "look for grants." The following are high-value starting points:

Resource	Statutory / Regulatory Basis	Why it matters	Primary Access Gateway & Directory
State Assistive Technology Act Programs (ACL/AT3)	29 U.S.C. §§ 3001–3007 (Assistive Tech Act)	Device demonstrations, short-term loans, reuse programs, financing, and state-specific acquisition assistance.	at3center.net
Medicare / Medicaid / Early and Periodic Screening, Diagnostic, and Treatment (EPSDT)	42 U.S.C. § 1395 et seq.; 42 U.S.C. § 1396d(r)	Potential coverage for DME, speech-generating devices, hearing-related equipment, and other medically necessary technology; rules vary by program and state. EPSDT covers broad AT for under-21s.	medicaid.gov
State Vocational Rehabilitation	29 U.S.C. § 723(a)(14) (Rehab Act / WIOA)	Potential funding when technology is necessary for employment or vocational goals.	rsa.ed.gov
IDEA / educational systems	20 U.S.C. § 1400; 34 C.F.R. § 300.105	For eligible students, technology required for a free appropriate public education may be the educational agency's responsibility rather than a trust expense.	ectacenter.org
ABLE accounts (529A)	26 U.S.C. § 529A; 26 C.F.R. § 1.529A-2	Express statutory coverage of assistive technology and related services as qualified disability expenses; may provide greater transactional flexibility.	ablenrc.org

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iCanConnect National Deaf-Blind Equipment Distribution Program (NDBEDP)	47 U.S.C. § 620 (FCC / CVAA)	Free telecommunications hardware and training for combined vision/hearing loss.	icanconnect.org
State Telecommunications Equipment Distribution Programs (TEDPs)	State Public Utility Commissions / Regulators	Free specialized landline/mobile phones, adaptive tablets, and signalers.	tedpa.org
Disability-Specific Nonprofits & Reuse	26 U.S.C. § 501(c)(3) Private Foundations	Potential grants, equipment programs, and condition-specific assistance; verify current eligibility and funding. State AT programs and nonprofits may offer gently used or refurbished equipment at reduced cost.	atia.org
Consumer Financial Protections Bureau (CFPB) Paying for Assistive Devices tool	Consumer Financial Protection Bureau	A consumer worksheet for comparing payment options and financing; useful as a client handout rather than legal authority.	consumerfinance.gov

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Technology is a Reasonable Expense:
A Practical Legal Framework for Technology-Related Distributions from Special Needs and Pooled Trusts

Eric J. Einhart, Esq.

Stetson Special Needs Trust Conference • Pooled Trust Intensive

October 21, 2026

CLE Written Materials

I. Why Technology Belongs in Special Needs Planning

A. The federal definition is functional, not product-specific

Technology can play an important role in helping a person with a disability communicate, work, learn, manage daily activities, navigate the community, live more independently, and participate in recreational and social activities. For attorneys engaged in special needs planning, the starting point may therefore be less about identifying a particular device and more about understanding the beneficiary's needs and considering whether technology could help address them.

The Assistive Technology Act provides a useful framework. It defines an assistive technology (AT) device as "any item, piece of equipment, or product system, whether acquired commercially, modified, or customized," that is used to increase, maintain, or improve the functional capabilities of a person with a disability.[1] The definition is broad enough to include both specialized equipment and commercially available technology. Depending on how it is used, a smartphone, tablet, computer, smartwatch, software application, or smart-home device may serve an assistive function even though it was not designed specifically for people with disabilities.

Federal health authorities take a similarly functional approach. National Institute of Child Health and Human Development (NICHD) describes AT as tools, equipment, and products that help people with disabilities function at home, school, work, and in the community. Its examples range from mobility devices and communication systems to cognitive aids, voice-recognition software, screen readers, mobile devices, and applications that assist with communication, memory, and other functions.[2] NICHD also recognizes that AT may promote independence and reduce the need for other support.[3]

For the practicing attorney, this suggests a useful way to approach technology in special needs planning: start with the beneficiary rather than the product. What activities are difficult? Where does

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[1] See 29 U.S.C. § 3002(4).

[2] See Eunice Kennedy Shriver Nat'l Inst. of Child Health & Human Dev., *Rehabilitative and Assistive Technology*; *What Are Some Types of Assistive Devices and How Are They Used?*. https://www.nichd.nih.gov/health/topics/factsheets/rehabtech

[3] See Eunice Kennedy Shriver Nat'l Inst. of Child Health & Human Dev., *How Does Rehabilitative Technology Benefit People with Disabilities?*. https://www.nichd.nih.gov/health/topics/rehabtech/conditioninfo/help

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the beneficiary rely on assistance from others? Are there barriers to communication, mobility, employment, education, safety, recreation, or community participation? Technology may not provide the solution in every case, but identifying those needs can help counsel, the beneficiary, the family, and other professionals determine whether there is a technology that could improve the beneficiary's functioning or quality of life.

Once a potentially useful technology is identified, the analysis can turn to how it might be acquired and paid for. Depending on the circumstances, funding may be available through Medicaid, Medicare, private insurance, vocational rehabilitation, educational programs, an ABLE account, grants, or other programs. A special needs trust or pooled trust may also be a potential source of payment, subject to the terms of the trust, the trustee's discretion, applicable public-benefit rules, and any other legal requirements discussed below.

B. Consumer Technology and Assistive Technology Increasingly Overlap

The distinction between specialized assistive technology and mainstream consumer technology is increasingly less important. A device does not necessarily have to be designed for people with disabilities to serve an assistive function. The Administration for Community Living ("ACL"), which administers the Assistive Technology Act programs, recognizes that assistive technology may include consumer electronics and mainstream products such as smartphones, tablets, smart speakers, wearable devices, and home-automation technology when those tools help a person maintain or improve functioning or independence.[4]

The same principle can be seen in practice. Princeton University's Office of Disability Services identifies commercially available technologies such as voice control and dictation, screen readers, text-to-speech, note-taking applications, noise-canceling headphones, Optical Character Recognition (OCR), Global Positioning System (GPS) and navigation applications, wearable technology, and Augmentative and Alternative Communication (AAC) applications among technologies that may assist individuals with different disabilities.[5]

Federal disability law provides additional context. Department of Justice's (DOJ) guidance under the Americans with Disabilities Act (ADA) identifies technologies such as screen readers, magnification software, optical readers, captioning, videophones, assistive listening systems, and accessible electronic information as examples of auxiliary aids and services that may be used to provide effective communication.[6] The ADA does not govern whether an SNT or pooled trust may purchase these technologies, but the guidance reinforces the broader point that technology can be an important means of improving communication and access for people with disabilities.

For counsel, the practical takeaway is to look beyond products labeled "assistive technology." A smartphone, tablet, computer, wearable device, application, or smart-home product may warrant consideration because of what it allows the particular beneficiary to do. Once a potentially useful

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[4] See Administration for Community Living, *Assistive Technology: Tools to Improve the Everyday*; Administration for Community Living, *National Assistive Technology Awareness Day* (Apr. 22, 2026). https://acl.gov/news-and-events/acl-blog/national-assistive-technology-awareness-day

[5] See Princeton Univ. Office of Disability Servs., *Assistive Technology* and related disability-specific assistive technology resources. https://ods.princeton.edu/assistive-technology

[6] See U.S. Dep't of Justice, Civil Rights Div., *ADA Requirements: Effective Communication*. https://www.ada.gov/resources/effective-communication/

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technology is identified, counsel can then consider whether the trust is an appropriate source of payment and what information may help the trustee evaluate the request.

II. The Governing Legal Framework

A. The Pooled-Trust Statute Establishes the Structure, Not a List of Permitted Expenses

For a beneficiary-funded pooled trust account to qualify under 42 U.S.C. § 1396p(d)(4)(C), the trust must be established and managed by a nonprofit association, maintain a separate account for each beneficiary while permitting funds to be pooled for investment and management, establish accounts solely for the benefit of individuals with disabilities, and satisfy the statutory requirements concerning amounts remaining at the beneficiary's death.[7] Neither the statute nor the corresponding federal requirements provide a list of permitted lifetime expenditures.

Lewis v. Alexander is a helpful case on this point. In this case, the Third Circuit invalidated a Pennsylvania law requiring every pooled-trust expenditure to have a "reasonable relationship to the needs of the beneficiary," concluding that the federal Medicaid statute imposed no such restriction on the purposes for which pooled-trust funds could be spent.[8] *Lewis* does not eliminate the terms of the trust, applicable fiduciary law, the sole-benefit requirement, or the public-benefit consequences of a particular distribution. Nor does it require a pooled-trust administrator, state court, or other decision-maker to approve a particular expenditure merely because federal law does not prohibit it. The master trust and joinder agreement may impose additional requirements, the nonprofit association may have established distribution procedures consistent with those instruments, and applicable state fiduciary law or judicial supervision may impose additional constraints. Lewis instead cautions against treating restrictions that Congress did not include in § 1396p(d)(4)(C) as additional federal statutory requirements.

Other cases illustrate the broader supplemental role these trusts may serve. In *Center for Special Needs Trust Administration, Inc. v. Olson*, the Eighth Circuit described a pooled special needs trust as paying expenses not covered by Medicaid, giving clothing, phone service, vehicle maintenance, and taxes as examples.[9] The court's description is not a list of approved expenditures, but it is a useful reminder that pooled-trust distributions are not limited to medical care or specialized disability equipment.

B. The Trust Instrument and Fiduciary Law Remain Central

Whether a particular technology expense is appropriate will ordinarily require counsel to look beyond the federal pooled-trust statute. The master trust and joinder agreement may address the trustee's discretion, distribution standard, sole-benefit requirements, ownership of purchased assets,

[7] 42 U.S.C. § 1396p(d)(4)(C); see also SSA POMS SI 01120.203.D.
[8] *Lewis v. Alexander*, 685 F.3d 325, 347–49 (3d Cir. 2012).
[9] *Ctr. for Special Needs Tr. Admin., Inc. v. Olson*, 676 F.3d 688, 695 (8th Cir. 2012).

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reimbursement procedures, and other conditions affecting distributions. State trust law and the trustee's fiduciary duties may also affect the analysis.[10]

In practice, pooled-trust administrators may also have their own procedures for reviewing distribution requests. Before developing extensive documentation, counsel may want to determine what the particular trustee requires for the type and amount of expenditure being considered. A request for a modest consumer device may be handled differently from a substantial home-automation project or specialized communication system.

The practical inquiry therefore begins with the governing trust: What authority does the trustee have, what limitations apply, and what information does the trustee need to exercise that discretion?

C. For an SSI Recipient, the Distribution Must Also Be Analyzed Under SSI Income and Resource Rules

A separate question is whether the manner in which the trust pays for technology will affect the beneficiary's SSI. SSA's POMS provides particularly useful guidance on this issue, although the POMS addresses SSI administration rather than whether a trustee is authorized under the governing trust to make the expenditure.

When the trust principal is not a countable resource, cash paid directly to the beneficiary generally constitutes unearned income. By contrast, a payment to a third party that results in the beneficiary receiving a non-cash item, other than shelter, generally will not be income if the item would be an excluded non-liquid resource if retained into the following month.[11]

SSA provides a particularly relevant example: if a trust purchases a computer for the beneficiary, the computer is not income because it would be excluded as a household good in the following month.[12] The POMS separately identifies electronic equipment, including computers and televisions, as household goods excluded from resources regardless of value. It also excludes personal effects, including items required because of a physical or mental impairment. Property acquired or held because of its value or as an investment is treated differently.[13]

The exclusion of the computer as a resource should be distinguished from the SSI treatment of the funds used to acquire it. If the trust purchases the computer directly from a vendor, the beneficiary generally receives the excluded non-cash item rather than cash. If the trust instead distributes cash directly to the beneficiary to purchase the computer, the cash generally constitutes unearned income when received, even though the computer ultimately purchased with it may be an excluded household good. Any cash remaining into the following month must also be analyzed under the SSI resource rules. Similarly, loading funds onto a beneficiary-owned prepaid-card account may produce income and resource consequences that would not arise from a direct vendor payment or a properly structured trustee-controlled payment method. The analysis therefore requires counsel to consider both what the beneficiary ultimately receives and how the purchase is funded.

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[10] See *Lewis*, 685 F.3d at 348–49 (recognizing that special needs trusts remain subject to state trust law and mechanisms for enforcing trustees' fiduciary duties); SSA POMS SI 01120.203.D.1 (recognizing that pooled-trust instruments generally consist of a master trust and a beneficiary-specific joinder agreement).

[11] See SSA POMS SI 01120.201.I.1.a, c; see also SSA POMS SI 01120.200.E.1.

[12] SSA POMS SI 01120.201.I.1.c.

[13] 20 C.F.R. § 416.1216; SSA POMS SI 01130.430.B–C.

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Shelter expenses require separate attention. Effective September 30, 2024, SSA no longer includes food in its calculation of in-kind support and maintenance ("ISM"); ISM calculations now focus on shelter.[14] A trust payment of a beneficiary's shelter expense may therefore affect SSI even though the same payment may be authorized under the trust. For technology-related expenditures, counsel may want to consider the actual item or service being purchased rather than assume that all technology expenses receive the same SSI treatment.

D. The Method of Payment Can Affect the SSI Analysis

How the trust pays an expense can matter as much as what it purchases. Cash paid directly to the beneficiary generally constitutes unearned income, while payment directly to a vendor for many non-cash goods or services may not.[15]

The POMS also recognizes other payment methods. A reimbursement from the trust to a third party for funds spent on behalf of the beneficiary is not income to the beneficiary, although the underlying item received by the beneficiary must still be analyzed under the ordinary income rules.[16] That rule addresses the SSI treatment of the reimbursement; it does not eliminate the trustee's obligation to maintain adequate records showing what was purchased, for whom, and in what amount. This distinction can become particularly important with recurring technology expenses. Reimbursing a family member each month for a cellular plan, internet service, software subscription, or other expense charged to a personal account may require allocation of shared or mixed charges and sufficient documentation to establish the beneficiary's expense. Where feasible, direct vendor billing or another trustee- or administrator-controlled payment method may provide a cleaner administrative record for recurring expenses.

SSA also provides specific guidance for administrator-managed prepaid cards. Where the trustee owns and controls the account, the SSI treatment generally depends on what is purchased with the card. If the beneficiary owns the prepaid-card account, amounts loaded onto the card are treated differently and may constitute income and, if retained, a resource.[17] Gift cards and gift certificates present additional concerns because SSA may treat them as cash equivalents.[18]

For counsel, the practical point is not that every technology purchase must be paid directly to the vendor. Rather, it may be helpful to understand how the particular trust makes distributions and then consider the both the public-benefit consequences and the administrative record created by the proposed payment method before the transaction occurs.

E. ABLE Accounts Provide a Useful Comparison, but Apply a Different Legal Standard

ABLE accounts operate under a separate statutory framework, but their treatment of technology provides useful context. Congress included "assistive technology and personal support services" within the definition of qualified disability expenses.[19] Treasury regulations further provide that

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[14] See Omitting Food from In-Kind Support and Maintenance Calculations, 89 Fed. Reg. 21,508 (Mar. 29, 2024) (effective Sept. 30, 2024); SSA EM-24048, *Omitting Food from In-Kind Support and Maintenance Calculations*; see also SSA POMS SI 00835.001 et seq.

[15] See SSA POMS SI 01120.201.I.1.a, c.

[16] SSA POMS SI 01120.201.I.1.g.

[17] SSA POMS SI 01120.201.I.1.e.

[18] SSA POMS SI 01120.201.I.1.f; SI 00830.522.

[19] 26 U.S.C. § 529A(e)(5).

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qualified disability expenses may include basic living expenses and are not limited to expenses that are medically necessary or that solely benefit the individual with a disability.[20]

The regulations provide an unusually concrete technology example. They describe an individual whose impairment limits navigation and communication and conclude that the cost of buying, using, and maintaining a smartphone may constitute a qualified disability expense when the device helps the individual navigate and communicate more safely and effectively and thereby supports independence and quality of life.[21]

Those rules govern ABLE accounts, not special needs trusts, and should not be treated as authority that an SNT or pooled trust may make the same expenditure. They are nevertheless useful in demonstrating federal recognition that mainstream consumer technology can serve disability-related purposes and that the relevant expense may include not only acquisition of the device, but also its use and maintenance.

An ABLE account may also provide an additional funding option for an eligible beneficiary. SSA provides that funds transferred from a trust into the beneficiary's ABLE account are excluded from the beneficiary's income for SSI purposes.[22] Depending on the beneficiary's eligibility, the nature of the expense, contribution limits, the terms of the trust, and other circumstances, counsel may wish to consider whether payment through the trust, an ABLE account, or another available source offers the most appropriate approach.

III. Identifying the Right Technology and Potential Funding Sources

A. Start with the Beneficiary's Needs, Not the Device

When considering whether technology might benefit a client, a useful starting point is what the beneficiary wants or needs to do. Is there a difficulty with communication, memory, mobility, vision, hearing, navigation, safety, education, employment, recreation, or another aspect of daily life? Is the beneficiary relying on another person for a task that technology might allow the beneficiary to perform more independently?

NICHD describes the selection of assistive technology in similar terms, matching particular technologies to the individual's needs to help the person function more effectively or independently. Depending on the circumstances, that process may involve the beneficiary, family or caregivers, and professionals such as physicians, occupational therapists, speech-language pathologists, educators, rehabilitation engineers, or other specialists.[23]

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[20] 26 C.F.R. § 1.529A-2(h)(1).

[21] 26 C.F.R. § 1.529A-2(h)(2), Example 1.

[22] SSA POMS SI 01120.201.I.1.h; see also SSA POMS SI 01130.740.

[23] See Eunice Kennedy Shriver Nat'l Inst. of Child Health & Human Dev., *How Does Rehabilitative Technology Benefit People with Disabilities?* (explaining that assistive technology may be selected through the individual, caregivers, and professionals who match technologies to particular needs). https://acl.gov/AT

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The attorney does not need to become an assistive-technology expert. The practical role may instead be to recognize where technology could be useful, identify people or resources that can help evaluate the options, and then consider how an appropriate device or service might be acquired and paid for.

B. Consider Whether an Assessment, Demonstration, or Trial Would be Helpful

For some technology, the appropriate choice may be relatively straightforward. For a more expensive, specialized, or unfamiliar product, counsel may want to explore whether the beneficiary can try the technology before trust funds are committed.

State Assistive Technology Act Programs can be particularly useful. These programs offer device demonstrations and short-term loans that allow individuals to try equipment before purchasing it, as well as reuse programs and certain financing options.[24] The Department of Education has similarly recognized that demonstrations and short-term borrowing through State AT Programs can help determine whether a device is effective for a particular individual before it is purchased.[25]

Depending on the technology and the beneficiary's needs, input from an Occupational Therapist (OT), Physical Therapist (PT), Speech-Language Pathologist (SLP), audiologist, rehabilitation engineer, assistive-technology professional, educator, or other knowledgeable professional may also be helpful. Professional evaluation is not a universal prerequisite to a technology distribution from an SNT or pooled trust. Rather, it is one possible source of information that may help identify the right technology and, where appropriate, help the trustee understand the request.

C. Consider Other Potential Funding Sources

Once an appropriate technology has been identified, counsel may also want to consider what funding sources are available. Depending on the beneficiary, the technology, and its intended use, possible sources may include Medicare or Medicaid, private insurance, special education, vocational rehabilitation, employer-provided accommodations, an ABLE account, State AT Programs, grants, charitable programs, reuse programs, or the beneficiary's SNT or pooled trust.[26]

For example, under IDEA, if an IEP team determines that an assistive-technology device or service is required for a child to receive a free appropriate public education, the public agency is responsible for making the technology available. Federal regulations also recognize that school-purchased assistive technology may, on a case-by-case basis, need to be available for use at home or in other settings.[27] Other funding programs have their own eligibility standards, coverage rules, and limitations.

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[24] See Administration for Community Living, *Assistive Technology: Tools to Improve the Everyday* (describing State Assistive Technology Act Program device demonstrations, short-term loans, reuse programs, and financing options); see also 29 U.S.C. §§ 3003–3004.

[25] See U.S. Dep't of Educ., Office of Educ. Tech. & Office of Special Educ. Programs, *Myths and Facts Surrounding Assistive Technology Devices and Services* (Jan. 2024).

[26] See U.S. Dep't of Educ., *Myths and Facts Surrounding Assistive Technology Devices and Services* (Jan. 2024) (discussing multiple potential funding sources for AT) https://sites.ed.gov/idea/files/Myths-and-Facts-Surrounding-Assistive-Technology-Devices-01-22-2024.pdf; Administration for Community Living, *Assistive Technology: Tools to Improve the Everyday*. https://acl.gov/AT. Availability and coverage will depend on the particular program and beneficiary.

[27] See 20 U.S.C. § 1412(a)(1); 34 C.F.R. § 300.105; see also 34 C.F.R. §§ 300.5–300.6 (defining assistive technology devices and services).

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The existence of another possible funding source does not necessarily mean that the trust cannot or should not pay. Depending on the trust terms, the beneficiary's circumstances, the availability and timing of other funding, and the trustee's discretion, counsel may wish to explore the alternatives before deciding how to present the request. In some cases, another program may cover the entire expense. In others, the trust might be considered for an uncovered device, an upgrade, accessories, training, maintenance, a recurring service, or another cost that the primary program does not cover.

For attorneys unfamiliar with available technology or funding programs, the State AT Act Program can be a useful place to begin. Every state and territory receives federal AT Act funding, and the programs can assist individuals in identifying technology, trying devices, locating reuse opportunities, and exploring financing options.[28]

IV. Ten Technology Requests: What to consider

The following hypotheticals are not categorical answers or approval rules. Instead, they illustrate the questions counsel may want to consider when evaluating a technology-related request: What purpose does the technology serve for the beneficiary? What does the trust permit? Are there sole-benefit concerns? Could the purchase affect SSI or Medicaid? Is another source of payment available? How should the purchase be made? And what information would be helpful for the trustee in considering the request?

1. Smartphone and service

A beneficiary may use a smartphone for reminders, navigation, telehealth, medication management, communication with caregivers or support staff, emergency contact, or other everyday activities.

When considering a request for a smartphone and cellular service, counsel may want to identify how the beneficiary uses the device and consider the cost of the phone, service plan, accessories, and any recurring charges. The POMS identifies telephone bills as an example of third-party trust payments that may not constitute income to an SSI recipient.[29] Although the ABLE rules do not govern SNT distributions, they provide a useful comparison: the Treasury regulations specifically recognize a smartphone used for navigation and communication as a qualified disability expense.[30] Depending on the trust and the circumstances, counsel should consider the governing distribution standard and any applicable sole-benefit requirements. Counsel should also consider how recurring service charges will be paid and documented. Direct billing to the trust or another trustee-controlled payment method may be administratively preferable to repeated reimbursement of charges appearing on a family member's personal or shared cellular account, particularly where the bill includes services for multiple users.

2. Laptop or desktop computer

A beneficiary may use a computer for education, employment, telehealth, communication, managing benefits or finances, recreation, or other everyday activities.

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[28] See 29 U.S.C. §§ 3003–3004; Administration for Community Living, *Assistive Technology: Tools to Improve the Everyday*. https://acl.gov/AT

[29] See SSA POMS SI 01120.200.E.1.c; SI 01120.201.I.

[30] See 26 C.F.R. § 1.529A-2(h)(2) (Example 1).

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For an SSI recipient, the POMS provides a helpful example: when a trust purchases a computer for the beneficiary, the purchase is not treated as income because the computer would be excluded as a household good in the following month.[31] That result assumes that the transaction is structured so that the trust purchases the computer or otherwise makes a qualifying third-party payment. It should not be read to mean that the trustee can distribute cash to the beneficiary to purchase a computer without SSI consequences. Cash paid directly to the beneficiary generally constitutes unearned income when received, and any amount retained into the following month must be separately analyzed as a resource. The payment mechanism should therefore be considered along with the resource status of the computer itself.

Counsel may still want to consider the terms of the trust, the cost of the computer in relation to the trust's resources, and any applicable sole-benefit considerations. For a more expensive or specialized system, additional information about the beneficiary's intended use and the reason for the particular configuration may help the trustee evaluate the request.

3. Tablet used as an AAC device

A beneficiary with limited speech may use a tablet with speech-generating software, together with a protective case, mounting system, switch, or eye-gaze interface, as an augmentative and alternative communication (AAC) system. Federal law broadly defines assistive technology to include commercially available equipment used to improve functional capabilities, and NICHD specifically recognizes electronic and speech-generating devices as forms of AAC.[32]

When advising on a request, counsel should explain how the tablet and related components support the beneficiary's communication rather than simply describing the request as the purchase of an iPad or other consumer device. For a more expensive or specialized system, an SLP, OT, or assistive-technology assessment, trial results, and a vendor quote may help the trustee evaluate the request. Counsel may also wish to explore whether Medicaid, Medicare, private insurance, a school program, or another available source may cover some or all of the cost.[33]

If trust funds will be used, counsel should separately consider the method of payment. The fact that the tablet itself may qualify as an excluded household good or personal effect does not make a cash distribution to the beneficiary SSI-neutral. Direct vendor payment or another properly structured trustee-controlled payment method generally avoids giving the beneficiary cash merely to acquire an otherwise excludable device.

4. Home internet

A beneficiary may rely on home internet for telehealth, work, education, communication, social connection, or access to medical and benefit information.

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[31] See SSA POMS SI 01120.201.I.1.c; SSA POMS SI 01130.430.B–C.1.

[32] 29 U.S.C. § 3002(4); Eunice Kennedy Shriver Nat'l Inst. of Child Health & Human Dev., *Rehabilitation Medicine Activities* (identifying electronic and speech-generating devices as forms of AAC).

[33] See 29 U.S.C. § 3002(5)(A)–(C) (including evaluation, acquisition, selection, fitting, customization, adaptation, maintenance, repair, and replacement within the definition of assistive technology services); U.S. Dep't of Justice, *ADA Requirements: Effective Communication*.

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Counsel may want to consider how the beneficiary uses the service, the monthly cost and available service options, and whether the internet is shared with other household members. For SSI purposes, current POMS identifies certain trust payments to third parties, including phone bills, as examples of disbursements that generally are not income, while separately addressing payments for food and shelter.[34] Where the service is shared, counsel may also want to consider the applicable sole-benefit rules and whether payment of all or some portion of the expense is appropriate under the circumstances.[35]

The recurring nature of the expense also warrants attention to payment mechanics and recordkeeping. If the service is billed through a family member's personal account or bundled with other household services, repeated reimbursement may require the trustee to identify and document the beneficiary's appropriate share. Where available and consistent with the trust's procedures, direct vendor billing, a separately identifiable beneficiary account, or another administrator-controlled payment arrangement may simplify both the distribution analysis and later trust accounting.

5. Smart-home environmental controls

A beneficiary with limited mobility or dexterity may request voice-controlled lights, door locks, thermostats, video doorbells, or similar technology to allow greater control over the home environment. Counsel may want to explain how the technology will help the beneficiary and, particularly with a larger or more expensive system, whether there are other funding options to consider.[36]

Because smart-home technology often benefits others in the household, shared use may also be worth addressing. For trusts subject to the sole-benefit requirement, the POMS recognizes that a purchase may primarily benefit the beneficiary even when others receive some incidental benefit. More substantial installations may warrant additional consideration of cost, ownership of the home, and whether some allocation of the expense is appropriate.[37]

6. Wearable technology

A beneficiary may request a smartwatch or other wearable device for fall detection, reminders, emergency calling, location sharing, health alerts, or similar functions.

Counsel may want to consider how the beneficiary will use the device, its cost, and whether there are recurring expenses for cellular service, monitoring, or applications. Depending on the cost and intended use, a brief explanation from the beneficiary or family may be sufficient, while a more expensive device or one intended to address a particular medical or safety concern may benefit from additional support from a physician, therapist, or care manager. Counsel may also wish to explore

[34] SSA POMS SI 01120.200.E.1.b–c; SI 01120.201.I.
[35] SSA POMS SI 01120.200.E.1.b–c; SI 01120.201.I.
[36] See Princeton Univ. Office of Disability Servs., *Assistive Technology for Mobility Disabilities*. https://ods.princeton.edu/assistive-technology
[37] SSA POMS SI 01120.201.F.3.a.

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whether insurance or another program will cover a device designed for the beneficiary's particular needs.[38]

7. Screen reader, magnification, OCR, or visual-assistance technology

A beneficiary who is blind or has low vision may request technology such as screen-reading or magnification software, a refreshable braille display, an OCR application, a digital magnifier, smart glasses, a navigation tool, or a remote visual-assistance service. Many of these technologies are well-established accessibility tools. The Department of Justice identifies screen readers and similar technologies in its guidance on effective communication, and Princeton University's Office of Disability Services identifies a range of technologies used by people who are blind or have low vision, including screen readers, braille displays, OCR software, magnification tools, voice assistants, GPS applications, and wearable technology.[39]

For counsel advising a beneficiary or family, it may be helpful to begin with what the beneficiary is trying to accomplish rather than with the particular device or product being requested. The appropriate technology may depend on the beneficiary's vision, existing technology, living situation, work or educational environment, comfort with the device, and other individual circumstances. For a more expensive or specialized product, counsel may also want to explore whether an assessment, demonstration, or trial period is available before trust funds are committed.

The trust is one possible source of payment, but it may not be the only one. Depending on the beneficiary and the intended use of the technology, counsel may want to explore whether the device or service is available through another program or funding source before presenting the request to the trustee. The availability of another funding source does not necessarily mean that the trust cannot pay for the technology. Rather, it may be one of the practical considerations in determining how best to obtain the technology for the beneficiary.

If trust funds are being considered, the attorney may want to review the terms of the trust, the trustee's distribution procedures, the cost and expected useful life of the technology, any recurring subscription or service charges, and the beneficiary's public benefits. For an SSI recipient, the method of payment may also be relevant. SSA generally provides that a third-party trust payment resulting in the beneficiary's receipt of a non-cash item, other than food or shelter, is not income if the item would be an excluded non-liquid resource if retained into the following month.[40] The POMS uses the trust's purchase of a computer as one example of this rule.[41]

For a first-party special needs trust or pooled trust subject to the sole-benefit requirement, counsel may also want to consider whether the technology is being purchased primarily for the beneficiary's

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[38] See, e.g., Shomir Chaudhuri, Hilaire Thompson & George Demiris, *Fall Detection Devices and Their Use with Older Adults: A Systematic Review*, 37 J. Geriatric Physical Therapy 178 (2014)

[39] See U.S. Dep't of Justice, Civil Rights Div., *ADA Requirements: Effective Communication*, https://www.ada.gov/resources/effective-communication/; Princeton Univ. Office of Disability Servs., *Assistive Technology for Visual Disability*, https://ods.princeton.edu/assistive-technology/visual-disability.

[40] SSA POMS SI 01120.201.I.1.a, c; see also SSA POMS SI 01120.200.E.1.c (addressing third-party trust disbursements).

[41] SSA POMS SI 01120.201.I.1.c; SSA POMS SI 01120.200.E.1.c.

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use and benefit. SSA's guidance recognizes that a purchase may primarily benefit the beneficiary even though another person receives some incidental benefit from it.[42]

The practical role of counsel is likely going to be to help develop the facts necessary for the trustee to evaluate the request: What does the beneficiary need or want to accomplish? Why was this particular technology selected? What will it cost? Are there other potential sources of payment? Are there recurring costs? And is there anything about the proposed purchase or payment method that could affect the beneficiary's public benefits? The answers will vary from one beneficiary and one technology request to another.

8. Noise-cancelling headphones and sensory-regulation technology

A beneficiary with autism, sensory sensitivities, attention challenges, or another disability may use noise-cancelling headphones, white-noise applications, or similar technology to reduce background noise, improve concentration, or manage sensory input at school, work, while traveling, or in other community settings. Princeton University's Office of Disability Services, for example, identifies noise-cancelling headphones and white-noise applications as assistive technologies that may support focus and sensory regulation.[43]

This kind of request may be relatively straightforward, but counsel may still want to consider the purpose of the technology in the context of the particular beneficiary. Rather than focusing on whether headphones are generally considered "assistive technology," it may be more useful to explain how the beneficiary intends to use them and the benefit they are expected to provide. Depending on the circumstances, that explanation may come from the beneficiary or family, or it may be supported by a teacher, therapist, physician, case manager, or other professional familiar with the beneficiary.

The amount of documentation appropriate for the request may also depend on the circumstances. A trustee considering a modest purchase of commercially available headphones may not require the same information that would be helpful when considering a more expensive or specialized sensory-regulation system. Counsel should check the trust's distribution procedures before obtaining professional documentation that may not be necessary.

For an SSI recipient, the manner in which the purchase is made should also be considered. SSA's POMS generally provides that a trust payment to a third party for a non-cash item, other than food or shelter, will not constitute income if the item would be an excluded non-liquid resource if retained into the following month.[44] For a first-party special needs trust or pooled trust subject to the sole-benefit rules, counsel may also want to consider who will use the equipment. SSA provides that goods or services purchased from a third party should be for the beneficiary's primary benefit, while

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[42] SSA POMS SI 01120.201.F.3.a (providing that goods or services purchased from a third party must be for the beneficiary's "primary benefit," while recognizing that a collateral benefit to another person does not necessarily violate the sole-benefit requirement).

[43] Princeton Univ. Office of Disability Servs., *Assistive Technology for Cognitive Disability*, https://ods.princeton.edu/assistive-technology/cognitive-disability.

[44] SSA POMS SI 01120.201.I.1.a, c. The POMS further provides that a trust's purchase of a computer for a beneficiary does not constitute income where the computer would be excluded as a household good in the following month.

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recognizing that some incidental benefit to another person does not necessarily violate the sole-benefit requirement.[45]

In many cases, the practical inquiry may be as simple as identifying: What does the beneficiary use the technology for, who will use it, what does it cost, and is the proposed method of payment consistent with the trust and the beneficiary's public benefits? More extensive documentation may be useful where the cost, proposed use, or circumstances warrant it, but the analysis should remain proportionate to the particular request.

9. Gaming system or gaming computer

A beneficiary requests a gaming system used for recreation, online friendships, adaptive gaming, and participation with peers.

Recreation and entertainment are among the examples identified in the POMS of third-party trust disbursements that may not be treated as income to the beneficiary for SSI purposes.[46]

Whether a particular expenditure is appropriate, however, will depend on the terms of the trust, the beneficiary's circumstances, and the trustee's exercise of discretion.

When discussing a recreational technology request with a client, it may be helpful to consider the cost of the item, how often it will be used, the resources available in the trust, whether others will also use or benefit from it, any applicable sole-benefit considerations, and how the technology may contribute to the beneficiary's recreation, social participation, or quality of life.

There may be circumstances where a disability-related or therapeutic purpose supports the request, but there is no reason to characterize an expenditure that way unless the facts support it. If the primary purpose is recreation or social participation, it may be more appropriate to simply explain that purpose and allow the trustee to consider the request in light of the trust terms and the beneficiary's individual circumstances.

10. AI Subscription or AI-enabled Tool

A beneficiary with cognitive, executive-functioning, communication, sensory, or other limitations may seek to use an AI-enabled application for purposes such as simplifying written material, organizing tasks, drafting or revising communications, generating reminders, or otherwise assisting with activities that the beneficiary finds difficult to perform independently.

Can trust funds be used to pay for an AI tool or subscription?

There does not appear to be a special rule under federal special needs trust law or current SSA guidance that specifically addresses generative AI or AI-based software subscriptions. Accordingly, counsel should be cautious about treating AI either as a categorically permissible trust expenditure or as a categorically impermissible one. Instead, the request should generally be evaluated under the same trust, fiduciary, and public-benefit principles applicable to other purchases of software, services, and technology.

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[45] SSA POMS SI 01120.201.F.3.a (providing that goods or services purchased by a trust from a third party must be for the beneficiary's "primary benefit," while cautioning that the rule should not be applied so strictly as to preclude incidental benefit to others).

[46] SSA POMS SI 01120.201.I.1.c; SSA POMS SI 01120.200.E.1.c.

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SSA's POMS provides useful, although not AI-specific, guidance. For SSI purposes, third-party trust payments that do not result in the beneficiary's receipt of cash, food, shelter, or a non-excluded resource generally may avoid treatment as income. SSA identifies expenditures such as educational expenses, therapy, phone bills, recreation, and entertainment as examples and expressly notes that its list is illustrative rather than exhaustive. For first-party trusts subject to the sole-benefit requirement, SSA further provides that a third-party payment for goods or services may satisfy that requirement when the goods or services are for the beneficiary's primary benefit, even if another person receives some incidental benefit.[47]

Counsel may want to approach the request through an individualized analysis rather than a categorical answer. Relevant considerations include:

1. **Purpose and benefit to the beneficiary** – What will the beneficiary use the tool to do, and how will that use benefit the beneficiary? Where the request is based on a disability-related function, counsel may explain that connection. The Assistive Technology Act's broad definition of an assistive technology device may provide useful context when a commercially available technology is being used to increase, maintain, or improve the functional capabilities of an individual with a disability, although that statute does not itself determine whether an SNT may purchase the technology.[48]
2. **Governing Trust and Trustee discretion** – Does the governing instrument permit the expenditure under its applicable distribution standard? The fact that software incorporates artificial intelligence should not substitute for the ordinary analysis of the trustee's authority and fiduciary responsibilities.
3. **Public-Benefit Consequences and Payment Method** – Counsel should consider the beneficiary's particular benefits and the manner in which the expenditure will be made. For an SSI recipient, for example, payment directly to the beneficiary generally presents different income consequences from a qualifying payment by the trust to a third party for goods or services.[49]
4. **Nature of the Subscription and Use** – Consider who will hold the account, who will use it, whether the subscription is individual or shared, what services are included, whether the expense is recurring, and whether continued payment remains appropriate over time.
5. **Cost and Supporting Documentation** – The appropriate level of documentation may depend on the amount and nature of the expenditure. A relatively modest software subscription used by the beneficiary may present a different administrative question from an expensive AI-enabled system represented as addressing a particular communication, cognitive, educational, vocational, or health-related need.
6. **Privacy, Security, and Reliability** – Depending on the beneficiary and proposed use, counsel and the trustee may also wish to consider whether the application will receive sensitive personal, financial, health, or legal information; whether the beneficiary understands the

[47] SSA POMS SI 01120.201.F.3.a, I.1; see also SSA POMS SI 01120.200.E.1.c. SSA describes the relevant sole-benefit inquiry as whether third-party goods or services are for the beneficiary's "primary benefit" and cautions against applying the rule so strictly as to prohibit incidental benefit to others.
[48] 29 U.S.C. § 3002(4) (defining an assistive technology device broadly as a commercially acquired, modified, or customized item, equipment, or product system used to increase, maintain, or improve functional capabilities)
[49] SSA POMS SI 01120.201.I.1.a–d

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limitations of the technology; and whether human oversight is appropriate for consequential uses.

V. A Practical Technology Distribution Checklist

When a beneficiary or family asks whether the trust can pay for technology, counsel can work through the following checklist before contacting the trustee:

- ✓ **Identify the item precisely.** Hardware, software, accessories, installation, warranty, subscription, data plan, training, repairs, and replacement are separate cost components.
- ✓ **Identify the functional problem.** What task, barrier, safety issue, communication need, educational goal, employment goal, or quality-of-life objective does the technology address?
- ✓ **Read the governing instrument.** What distribution standard applies? Who has discretion? Are there special procedures, ownership rules, or restrictions?
- ✓ **Apply the sole-benefit rule where applicable.** Who will own and use the item? Will others receive more than incidental benefit? Does shared use require allocation or additional explanation?
- ✓ **Analyze SSI consequences.** Is the proposed distribution cash, a vendor payment, third-party reimbursement, credit-card payment, restricted prepaid card, gift card, or ABLE transfer? What item will the beneficiary actually receive?
- ✓ **Analyze Medicaid and other benefits separately.** Do not assume that an SSI-safe transaction resolves every Medicaid, waiver, housing, SNAP, or state-law issue.
- ✓ **Identify other potential funding sources or resources.** Medicare, Medicaid, private insurance, school, vocational rehabilitation, employer accommodation, state AT program, ABLE, grant, reuse program, or financing?
- ✓ **Determine the appropriate level of documentation.** Ordinary consumer purchase, specialized AT, high-cost system, home modification, or shared household technology?
- ✓ **Test before buying when feasible.** Use State AT Act demonstrations, short-term loans, vendor trials, or professional assessments.
- ✓ **Document the request.** Provide the functional justification, quote/invoice, payment method, supporting evaluation if appropriate, recurring costs, and confirmation of who will use/own the item.
- ✓ **Plan for the life cycle.** Training, software updates, connectivity, repairs, batteries, replacement, data security, account credentials, and eventual disposal can matter as much as the initial purchase.

VI. Model Anatomy of a Strong Distribution Request

A good request should be short enough to be processed but complete enough to answer the trustee's predictable questions. It should generally contain:

- Beneficiary and subaccount identification.
- Exact item, vendor, total price, accessories, taxes, installation, and recurring charges.
- Functional purpose stated in beneficiary-centered terms.
- Connection to the trust's distribution standard and, where applicable, the sole-benefit requirement.
- Public-benefit treatment and proposed payment method.

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- Other payer analysis when relevant.
- Professional recommendation or assessment when proportionate to the cost or complexity.
- Quote, invoice, product link, or other documentation required by the pooled trust.

Illustrative Request – AAC Tablet

The beneficiary seeks a tablet, protective case, AAC software, and mounting system for use as an augmentative communication device. The request must detail the beneficiary's expressive-communication limitations, specify the AAC application and access method, and explain how the device will be used with caregivers, medical providers, school or employment personnel, and family. Any recommendations from a Speech-Language Pathologist (SLP), Occupational Therapist (OT), or Assistive Technology Professional (ATP) must be attached. Additionally, the submission must confirm whether Medicaid, private insurance, or the school system was explored, noting that counsel should not assert Medicaid non-coverage without prior investigation. Finally, the request should identify the vendor and total cost, requesting payment through the pooled trust's approved vendor-payment or reimbursement procedure. Counsel should not assert that Medicaid never covers the device unless coverage has actually been investigated.

Illustrative Request – Smart-Home Accessibility

The beneficiary seeks voice-controlled lighting, locks, and environmental controls because limited mobility prevents safe, independent operation of conventional controls. The request must identify each component and explain the specific task it enables the beneficiary to perform. Additionally, it should address system installation and ownership, detail any incidental benefit to other household members, and justify why the expenditure remains primarily for the beneficiary's sole benefit. A formal vendor quote must be attached. If the installation materially improves real property owned by someone other than the beneficiary or the trust, counsel must separately analyze potential fiduciary and transfer-of-resource concerns.

VIII. Practice Points and Cautions

Do not over-medicalize ordinary life. A technology expense does not necessarily need to be medically necessary or therapeutic to warrant consideration. For SSI purposes, the POMS identifies phone bills, education, recreation, and entertainment among examples of third-party trust payments that may not constitute income.[50] That does not determine whether a trustee should approve a particular expenditure, but it is an important reminder that the SSI rules are not limited to medical expenses. Depending on the trust terms and the beneficiary's circumstances, counsel may wish to explain the actual purpose of the technology rather than create a medical justification that the facts do not support.

Separate trustee authority from public-benefit consequences. A distribution that does not count as income or a resource for SSI purposes is not automatically authorized by the trust. Counsel should separately consider the governing instrument, applicable fiduciary law, and, for first-party SNTs and pooled trusts, any applicable sole-benefit requirements.[51] The reverse is also important: an

[50] See SSA POMS SI 01120.200.E.1.c; SI 01120.201.I.1.c.
[51] See 42 U.S.C. § 1396p(d)(4)(A), (C); SSA POMS SI 01120.201.F; SI 01120.203.

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expenditure that the trustee is willing and authorized to make may still affect SSI or another means-tested benefit depending on what is purchased and how the payment is made.[52]

Do not assume the trust is always the payer of last resort. Other funding sources may be worth exploring, particularly where another program may cover the technology or provide an assessment, demonstration, or trial. But there is no single federal rule requiring every available funding source to be exhausted before an SNT or pooled trust may make a distribution. Whether another payer should be pursued first may depend on the governing trust, the particular benefit program, the availability and timing of other funding, and the beneficiary's circumstances.

Consider the method of payment. Direct payment to a vendor is often straightforward, but it is not the only payment method addressed by SSA. The POMS also provides rules for third-party reimbursements and administrator-managed prepaid cards.[53] Before advising a beneficiary or family, counsel may want to understand the trustee's distribution procedures and consider how the proposed payment method will be treated under the beneficiary's applicable benefit programs.

Do not promise approval. Even a well-supported request remains subject to the governing trust and the trustee's exercise of discretion. Pooled trusts may also have different distribution procedures and documentation requirements. Counsel can help identify the beneficiary's need, analyze the legal and public-benefit issues, and present the information that may assist the trustee in evaluating the request, while making clear to the client that the ultimate decision rests with the trustee.

Use the strongest authority available. Secondary sources can be useful for identifying issues, technology, and potential funding programs. When analyzing the legal consequences of a distribution, however, counsel should look first to the governing trust and applicable primary authority, including statutes, regulations, controlling case law, and relevant state law. SSA's POMS, while not itself a statute or regulation, is particularly useful for understanding how SSA administers the SSI income, resource, trust, and sole-benefit rules.[54]

IX. Conclusion

Technology is not inherently a reasonable trust expense, but neither should it be viewed as outside the ordinary scope of special needs planning simply because it is new, commercially available, or used by people without disabilities. Federal law recognizes assistive technology in functional terms, and SSA's rules provide a framework for determining how particular trust distributions will be treated for SSI purposes.[55] The ultimate analysis, however, remains individualized and depends on the

[52] See SSA POMS SI 01120.200.E; SI 01120.201.I.
[53] See SSA POMS SI 01120.200.E.1.e, g; SI 01120.201.I.1.e, g.

[54] See, e.g., SSA POMS SI 01120.200–.203. The POMS provides SSA's operating instructions and should be distinguished from statutes, regulations, and controlling judicial authority.
[55] See 29 U.S.C. § 3002(4) (defining an assistive technology device functionally as an item, equipment, or product system used to increase, maintain, or improve the functional capabilities of individuals with disabilities); SSA POMS SI 01120.200.E; SI 01120.201.I (addressing the SSI treatment of trust disbursements, including cash payments and third-party payments for goods and services). See also 26 C.F.R. § 1.529A-2(h)(2), Example 1 (recognizing, in the separate ABLE context, the purchase, use, and maintenance of a smartphone as a qualified disability expense under the facts presented).

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beneficiary, the technology, the governing trust, applicable fiduciary and public-benefit rules, and the manner in which the expense will be paid.

For practitioners, most technology requests can be approached through a few practical questions:

1. **What does the beneficiary want or need to do, and could technology help?**
2. **What technology is appropriate, and what funding options are available?**
3. **Does the governing trust permit the expenditure, and what fiduciary, sole-benefit, or public-benefit issues should be considered?**
4. **How should the request be presented and, if approved, how should the transaction be structured?**

That framework does not depend on a particular device. It can be applied to a computer, smartphone, AAC device, wearable, smart-home system, subscription service, or technology that has not yet reached the market. The products will continue to change. The attorney's task remains largely the same: identify what may help the beneficiary, understand the available funding options, analyze the governing legal framework, and help present a well-supported request to the trustee.

X. Selected Authorities and Practice Resources

The following authorities and resources provide useful starting points when evaluating a technology-related distribution from a special needs trust or pooled trust. They are organized by the question counsel is trying to answer rather than by source type. Their relevance will depend on the type of trust, the beneficiary's public benefits, applicable state law, and the particular technology or expense under consideration.

A. Can the Trust Make the Distribution?

42 U.S.C. § 1396p(d)(4)(A), (C) — First-Party Special Needs and Pooled Trusts
Starting point for the federal statutory requirements applicable to first-party special needs trusts and pooled trusts. Section 1396p(d)(4)(C) establishes the requirements for a qualifying pooled trust, including nonprofit management, separate beneficiary accounts, pooling for investment and management, sole benefit, and post-death retention or Medicaid reimbursement. It does not provide a list of permitted lifetime expenditures.

SSA POMS SI 01120.203 — Exceptions to Counting Trusts Established on or After January 1, 2000
SSA's principal operating guidance concerning the statutory exceptions for first-party special needs trusts and pooled trusts. Particularly useful when determining whether a trust satisfies the requirements for exclusion under the SSI trust rules.

SSA POMS SI 01120.201.F — Sole-Benefit Requirement
Important for first-party trusts subject to the sole-benefit requirement. Counsel should consult this provision when a technology purchase will be shared, will benefit other household members, involves services provided by family members, or otherwise raises a question about whether the expenditure is primarily for the beneficiary.

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Lewis v. Alexander, 685 F.3d 325 (3d Cir. 2012)
Useful authority concerning the limits of additional state restrictions on pooled trusts. The Third Circuit rejected Pennsylvania's requirement that pooled-trust expenditures bear a "reasonable relationship" to the beneficiary's needs. The case is useful for understanding what § 1396p(d)(4)(C) itself requires, but it should not be read as displacing the governing trust, state fiduciary law, or public-benefit rules.

Center for Special Needs Trust Administration, Inc. v. Olson, 676 F.3d 688 (8th Cir. 2012)
Provides useful background on the supplemental role of pooled trusts. In describing pooled-trust expenditures, the court referenced expenses such as clothing, phone service, vehicle maintenance, and taxes. The examples are descriptive rather than a judicial list of approved expenditures.

The Governing Trust, Joinder Agreement, and Applicable State Trust Law
These remain essential authorities for any actual distribution request. Counsel should identify the applicable distribution standard, trustee discretion, ownership provisions, reimbursement procedures, administrative requirements, and any limitations imposed by the governing instrument or applicable state law.

B. How Will the Distribution Affect SSI?

SSA POMS SI 01120.200 — Information on Trusts
A principal starting point for determining the SSI treatment of third-party trusts and trust disbursements. The POMS identifies examples of third-party trust payments that may not constitute income, including education, therapy, uncovered medical services, phone bills, recreation, and entertainment. The examples are illustrative rather than exhaustive.

SSA POMS SI 01120.201.I — Disbursements from Trusts Established with an Individual's Assets
One of the most useful provisions for technology-related requests. It addresses cash distributions, third-party payments, credit-card payments, prepaid cards, gift cards, reimbursements, and transfers to ABLE accounts.

Of particular practical value, SSA expressly provides that when a trust purchases a computer for the beneficiary, the computer is not income because it would be an excluded household good in the following month.

SSA POMS SI 01130.430; 20 C.F.R. § 416.1216 — Household Goods and Personal Effects
Useful when determining whether technology received by the beneficiary will be an excluded resource. SSA specifically identifies electronic equipment, including computers and televisions, as household goods and excludes household goods and personal effects regardless of value, subject to the rules concerning property held for investment.

SSA POMS SI 00835.000 et seq. — In-Kind Support and Maintenance
Consult when a proposed distribution involves shelter. Effective September 30, 2024, food is no longer included in SSA's ISM calculations. Technology expenses should therefore be analyzed

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according to what is actually being purchased or paid rather than under a generalized rule about "technology."

SSA POMS SI 00830.522 — Gift Cards and Gift Certificates
Useful when a trustee, beneficiary, or family proposes using gift cards or similar payment mechanisms. Some cards may be treated as cash equivalents and can create income or resource consequences.

C. Could an ABLE Account Be Used?

26 U.S.C. § 529A — ABLE Accounts
The federal statutory framework for ABLE accounts. The definition of qualified disability expenses expressly includes "assistive technology and personal support services," together with education, housing, transportation, employment support, health, financial management, and other categories.

26 C.F.R. § 1.529A-2(h) — Qualified Disability Expenses
Particularly useful for technology planning. The regulation explains that qualified disability expenses are not limited to medically necessary expenses and includes an example in which the purchase, use, and maintenance of a smartphone qualify because the device assists an individual with navigation and communication and supports independence and quality of life.

The ABLE standard does not govern SNT distributions, but it can provide useful context and may identify an alternative payment vehicle.

SSA POMS SI 01130.740 — Achieving a Better Life Experience (ABLE) Accounts
SSA guidance concerning the treatment of ABLE accounts for SSI purposes.

SSA POMS SI 01120.201.I — Trust-to-ABLE Transfers
Consult when considering whether trust funds may be transferred to the beneficiary's ABLE account. SSA provides specific guidance concerning the SSI treatment of these transfers.

D. Is the Technology Assistive Technology?

29 U.S.C. § 3002(4) — Assistive Technology Device
A useful starting definition. Federal law defines an assistive technology device functionally as an item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that increases, maintains, or improves the functional capabilities of an individual with a disability.

The definition is particularly helpful when commercially available technology, rather than specialized disability equipment, is being considered.

29 U.S.C. § 3002(5) — Assistive Technology Service
Defines AT services broadly to include assistance with evaluating AT needs and selecting,

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acquiring, designing, fitting, adapting, maintaining, repairing, replacing, and using AT devices, as well as training and technical assistance.

Administration for Community Living — Assistive Technology: Tools to Improve the Everyday
A practical federal resource for understanding assistive technology and locating State Assistive Technology Act Programs. Particularly useful when counsel or the family does not yet know which device is appropriate.

NICHD — Rehabilitative and Assistive Technology
Useful federal health resource for identifying ways technology may assist with communication, mobility, cognition, daily activities, education, employment, and community participation. It can also help counsel identify the types of professionals who may be useful in evaluating specialized technology.

U.S. Department of Justice — ADA Requirements: Effective Communication
Useful background concerning established communication technologies, including screen readers, accessible electronic information, captioning, assistive listening systems, and other auxiliary aids and services. The ADA does not determine whether an SNT may purchase these technologies, but the guidance can help identify recognized accessibility tools.

E. Can the Beneficiary Try the Technology Before Purchasing It?

State Assistive Technology Act Programs
For many practitioners, this is one of the most useful resources in this bank. Federally funded State AT Programs provide services that may include:

- device demonstrations;
- short-term equipment loans;
- device reuse;
- information and referral; and
- financing resources.

These programs can be particularly valuable before a trust purchases an expensive or unfamiliar device.

Administration for Community Living — State AT Program Gateway
Federal starting point for locating State AT Programs and learning about available demonstration, loan, reuse, and financing services.

AT3 Center — State Assistive Technology Program Directory
Practical national directory for locating the applicable State AT Program and related resources.

F. Could Another Program Pay for the Technology?

Medicaid and State HCBS Programs
Medicaid coverage of assistive and supportive technology varies significantly by state, eligibility

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category, state plan, waiver, and particular service definition. Counsel should review the beneficiary's actual Medicaid program rather than assume national coverage or noncoverage.

CMS materials concerning HCBS recognize assistive technology and technology-enabled supports in various Medicaid contexts, but the beneficiary's particular state program controls whether a specific device or service is covered.

Medicare
Consider Medicare when the requested technology may qualify as covered durable medical equipment, a speech-generating device, or another covered item or service. Coverage requirements, including medical-necessity and supplier requirements, should be evaluated under the particular Medicare benefit involved.

IDEA — 20 U.S.C. § 1400 et seq.; 34 C.F.R. §§ 300.5, 300.6, 300.105
Important when the beneficiary is an eligible student. If an IEP team determines that an AT device or service is required as part of special education, related services, or supplementary aids and services, the public agency must make it available. School-purchased AT may also be required for use at home or in another setting when necessary for FAPE.

State Vocational Rehabilitation Programs — Rehabilitation Act / WIOA
Worth investigating when technology relates to employment, vocational training, or an employment goal. State vocational rehabilitation agencies may provide assistive technology and related services when the applicable program requirements are met.

Employer Accommodation Obligations — ADA Title I
Potentially relevant when technology is needed to enable an employee or applicant with a disability to perform a job or participate in the employment process. Whether an employer is responsible for a particular technology requires an individualized ADA analysis.

iCanConnect — National Deaf-Blind Equipment Distribution Program
FCC-supported program providing communications equipment and related services to qualifying individuals with combined significant vision and hearing loss. Particularly useful before a trust purchases communications technology for an eligible beneficiary.

State Telecommunications Equipment Distribution Programs
State programs may provide specialized telecommunications equipment to qualifying residents with hearing, speech, vision, mobility, or other disabilities. Eligibility and available equipment vary by state.

G. Practical Technology and Funding Research

Consumer Financial Protection Bureau — Paying for Assistive Devices
A useful client-facing worksheet for identifying an assistive device, estimating costs, exploring insurance or other funding, and comparing financing options. Useful as a planning tool rather than legal authority.

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Princeton University Office of Disability Services — Assistive Technology Resources
A useful practical source for identifying currently available mainstream and specialized technologies, including screen readers, dictation, text-to-speech, OCR, navigation applications, noise-cancelling technology, AAC applications, and other accessibility tools. Useful for issue spotting rather than as authority governing trust distributions.

Disability-Specific Organizations
National and local organizations serving people with particular disabilities may maintain equipment programs, grants, lending libraries, technology demonstrations, or product information. Because programs and eligibility change, counsel should verify current availability before relying on a particular resource.

H. A Research Sequence for an Actual Technology Request

When a technology request reaches counsel's desk, the following research sequence can help keep the analysis focused:

1. **Start with the beneficiary.** What does the beneficiary want or need to accomplish, and what technology is being considered?
2. **Read the trust.** Identify the distribution standard, trustee discretion, sole-benefit requirements, ownership provisions, and distribution procedures.

3. **Identify the beneficiary's benefits.** Determine whether SSI, Medicaid, a Medicaid waiver, housing assistance, SNAP, or another means-tested program requires separate analysis.
4. **For SSI, start with the POMS.** Review SI 01120.200, SI 01120.201, SI 01120.203, and any resource or ISM provision applicable to the particular transaction.
5. **Check other potential funding sources.** Depending on the beneficiary, consider Medicaid, Medicare, IDEA, vocational rehabilitation, employer accommodations, ABLE, State AT Programs, and disability-specific programs.
6. **Investigate the technology.** For an unfamiliar or substantial purchase, consider a State AT Program demonstration or loan, professional evaluation, vendor trial, or other individualized assessment when appropriate.
7. **Analyze the payment method.** Determine whether the trustee proposes vendor payment, reimbursement, credit-card payment, prepaid card, ABLE transfer, or another method and analyze the public-benefit consequences of that method.
8. **Build the request.** Explain what the beneficiary seeks to accomplish, why the selected technology is appropriate, its total and recurring cost, who will use and own it, other funding investigated when relevant, and any supporting information proportionate to the request.

Core Research Set

For a practitioner who wants a shorter desk reference, these are the authorities and resources most likely to be useful repeatedly:

Trust and Distribution Law
- 42 U.S.C. § 1396p(d)(4)(A), (C)

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- Governing trust and joinder agreement
- Applicable state trust and fiduciary law
- *Lewis v. Alexander*, 685 F.3d 325 (3d Cir. 2012)
- *Center for Special Needs Trust Administration, Inc. v. Olson*, 676 F.3d 688 (8th Cir. 2012)

SSI
- SSA POMS SI 01120.200 — Trusts and trust disbursements
- SSA POMS SI 01120.201 — First-party trusts, sole benefit, and disbursements
- SSA POMS SI 01120.203 — SNT and pooled-trust exceptions
- SSA POMS SI 01130.430 — Household goods and personal effects
- SSA POMS SI 00835.000 et seq. — In-kind support and maintenance

ABLE
- 26 U.S.C. § 529A
- 26 C.F.R. § 1.529A-2(h)
- SSA POMS SI 01130.740

Assistive Technology
- 29 U.S.C. § 3002(4), (5)
- Administration for Community Living — Assistive Technology
- State Assistive Technology Act Programs
- NICHD — Rehabilitative and Assistive Technology

Potential Alternative Funding
- Medicaid / beneficiary's specific HCBS waiver or State Plan benefit
- Medicare
- IDEA, including 34 C.F.R. § 300.105
- State Vocational Rehabilitation
- Employer accommodation obligations where applicable
- iCanConnect and state telecommunications-equipment programs

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Technology is a Reasonable Expense

A Practical Legal Framework for Technology-Related Distributions from Pooled Trusts

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Estate Planning, Elder Law & Special Needs

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We Will Cover...



- Why Technology?
- Legal Framework
- Identifying the Right Tech
- Funding Sources
- Technology Requests
- Practical Strategies
- Q&A

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3



Why Technology

- Part of everyday life
- Communication
- Education & Employment
- Health & Safety
- Independent Living
- Recreation & Social Participation
- Community Access

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What is Assistive Technology



- Functional, not product-specific
- Specialized or commercially available
- Hardware, software & services
- Individualized to the beneficiary
- Independence & quality of life

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Consumer Tech Can be Assistive Tech



- Function matters more than the label
- Smartphones & tablets
- Computers & wearables
- Apps & software
- Smart-home technology
- AI-enabled tools

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Pooled Trust Legal Framework

- Federal pooled-trust statute
- Master Trust & Joinder Agreement
- Trustee discretion
- State fiduciary law
- Sole benefit
- Public-benefit rules
- No federal list of *approved* expenses



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Distributions to Pay for Tech

- **Can the trust make the distribution?**
  - Trust terms
  - Trustee discretion
  - Fiduciary / sole-benefit considerations
- **What happens if it does?**
  - SSI
  - Medicaid
  - Other means-tested benefits



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SSI: Payment Methods Matter

- Need to analyze the purchase carefully
- Method of payment can affect the SSI analysis
- Not all payments methods are created equal:
  - Cash
  - Vendor payment
  - Reimbursement
  - Prepaid card
  - Gift card
  - ABLE transfer

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Start with the Beneficiary

What does the beneficiary want or need to do?

- Communicate
- Remember
- Navigate
- See / Hear
- Work / Learn
- Live independently
- Participate
- Stay safe



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Finding the Right Tech



- Considerations
  - Beneficiary & family
  - Professionals
  - Assessment
  - Demonstration
  - Short-term loan
  - Vendor trial
  - State AT Programs
- ***You do/should NOT need to be the tech expert***

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Who might pay?

- Medicaid / Medicare
- Private insurance
- IDEA / School
- Vocational Rehabilitation
- Employer
- ABLE
- State AT Programs
- Grants / Charitable Programs
- Pooled Trust

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Think Beyond the Initial Purchaser

- There may be additional costs associated with the tech
- Consider
  - Device
  - Upgrade
  - Accessories
  - Installation
  - Training
  - Maintenance
  - Subscription / Service
  - Replacement



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Everyday Tech



- Smartphone & service
- Laptop / desktop
- Home internet
- Smartwatch / wearable
- Gaming system

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Assistive & Accessibility Tech



- AAC
- Screen reader
- Magnification / OCR
- Visual-assistance technology
- Sensory-regulation technology
- Smart-home environmental controls

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Emerging Technology



- AI-enabled applications
- Voice assistants
- Smart-home systems
- Wearable technology
- Remote support
- What's next?

Tech changes. The analytical framework doesn't.

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Evaluating a Tech Request

Before submitting a request ask the following:

- What is being requested?
- What does it do for the beneficiary?
- What does the trust permit?
- Sole-benefit issue?
- Public-benefit consequences?
- How will it be paid?

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Documentation Should be Proportionate

Consider the type and quantity of evidence for each request

$250 Headphones
↓
$1,500 Computer
↓
$5,000 AAC System
↓
$40,000 Smart-Home System

Cost + Complexity + Circumstances



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Build a Strong Request

- Exact item & total cost
- Beneficiary-centered purpose
- Who will use / own it?
- Payment method
- Recurring costs
- Other funding, when relevant
- Supporting information, when useful



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Practice Points

- Do not over-medicalize ordinary life
- Separate trust authority from benefit consequences
- Do not assume the trust is always payer of last resort
- Consider the method of payment
- Do not promise approval
- Use the strongest authority available



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QUESTIONS?



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STETSON LAW

Pooled Trusts Intensive

October 21, 2026

Missing Beneficiaries and Other Hard-to-Find Individuals: Practical Strategies for Trustees and Administrators

STETSON LAW

Center for Elder Justice

Access and Justice For All®

MISSING BENEFICIARIES AND OTHER HARD-TO-FIND INDIVIDUALS: PRACTICAL STRATEGIES FOR TRUSTEES AND ADMINISTRATORS

Haley D. Greer, JD
The Arc of Texas
Trust Director

THE PROBLEM OF THE DISAPPEARING BENEFICIARY

Pooled Trusts see beneficiaries move, changing relationships, death of caregivers, change of providers or representative payees. They didn't tell the Trust or someone on their behalf didn't. The Trust has been sending the statements to the provider, they don't bother to update the Trust, they just keep filing it away. You aren't notified that the beneficiary actually died or moved to another provider years ago.

Sometimes it's because the beneficiary doesn't have access to the ways you contacted them. The Trust is still sending the email but the beneficiary can't remember their passwords to their email, they lost the phone and phone number that was associated with the account and have no way to retrieve it. They forget to update the Trust, forgot they had a trust or just don't need to use it.

There were small breadcrumbs you could follow, but now that so many processes are electronic like SSA "checks" are no longer checks, bank and bills are electronic. Most beneficiaries don't own property or have a public footprint to follow.

Now the trust administrator can't find the beneficiary.

WHY FINDING THEM MATTERS – THE FIDUCIARY AND LEGAL ISSUES

Here are a few of the issues to consider when making the decision to locate missing beneficiaries:

1. The trust has an obligation to administer the trust
2. Duty to keep beneficiaries informed
3. Potential liability for not trying to properly locate a beneficiary
4. Making sure that payments are appropriate
5. Determining if the beneficiary is alive or dead
6. And more…

Every trust has its obligations outlined in the document, and all have an obligation to administer the trust according to its terms. The terms and trust law determine the potential liabilities that the trustee and administrator face. State and federal law may also impose duties on the Trustee and Administrator.

When a beneficiary cannot be located, a trustee and administrator should determine what obligations and liabilities arise within their trust documents, applicable law and fiduciary duties. At a minimum, the Trust should consider what reasonable efforts are appropriate to locate your beneficiaries while continuing to administer the account.

IS THE BENEFICIARY ACTUALLY MISSING?

Sometimes beneficiaries are not able to be located, but that doesn't mean that they are "missing". Some beneficiaries are just inactive, others a location can't be determined, and others can't be determined to be alive or dead. Then you have the beneficiary is legitimately missing, no one can locate them and police are involved.

Consider creating categories of beneficiaries who don't have appropriate contact information.

Quiet Beneficiary– You have tried to reach out but they do not respond. No return mail or other indication that the person is not at their last known address. They continue to receive communication but do not respond. This does not mean they are or are not missing.

Unable to Contact – they just may be hard to locate right now. These are the beneficiaries you know will reach out, but they only do so occasionally. You believe that they will reach out but don't have current contact information.

Whereabouts Unknown – Attempts to locate have been made but no current location can be verified.

Status Unknown – Cannot determine if this beneficiary is living or deceased.

Use these or similar categories when determining next steps within the search framework.

CREATE A SEARCH PROTOCOL

While I will talk specifically about beneficiaries here, this information can be used to locate anyone that is associated with the Trust or a specific Beneficiary.

Every trust should have a protocol in place for locating missing beneficiaries and/or their representatives. Think about when and how your trust is able to search. Think about what parts of this process you do in house vs. what you outsource.

Step 1 – Internal Records

Start with your CRM/Database and look at:

- Prior disbursement requests are often one of the best places to find information on locating a beneficiary. Invoices, utility payments, electronic payment information, ACH or bank information, True Link or similar card activity;
    - Look where payments have been made, who submitted the invoice and who provides care or services to the beneficiary.

    - Shipping Addresses- Look at where items are shipped on the amazon, Wal-Mart of other online purchases
- Joinder Agreement and supporting documents like court orders or other information included with the enrollment information;
- Current and prior: addresses, telephone numbers, email addresses;
- Prior tax documents; and
- Notes in CRM and correspondence.

Step 2 – Direct Contact

Reach out directly to the beneficiary and/or their representative.

- Call every known number for the beneficiary at different times of day.
- Text where permitted.
- Email every known address.
- Mail to current and prior addresses. Send certified mail when appropriate.
- Send correspondence marked "Address Service Requested" or use another USPS address-correction service when available.

Step 3 – Contact others in the Beneficiary's Orbit

Contact others who may have information about the Beneficiary's whereabouts. This is where the additional information gathered in step one is really utilized. Start using that information to find the Beneficiary. I recommend starting with the people who would have the most reliable information first and work your way down. That will look different depending on the person and their situation.

When you reach out, the communication should be – "Hi we are trying to locate Julie Smith. Can you have her reach out to us?" or "Do you know where Julie Smith is or how we can contact her?"

DO NOT SAY "Julie Smith has a trust worth $150,000 and we need to discuss her account" or anything of the sort. Do not indicate that she has a trust or that there are funds for her. Your goal is to locate the beneficiary, not explain to a third party why you are looking for them.

Reach out to current and former:

- Landlords, caregivers, residential providers, representative payees, guardians, case managers, pharmacies or medical providers identified on prior requests, prior attorneys or other vendors often provide breadcrumbs that lead to the beneficiary.

Step 4 – Internet, Social Media and Public Records

If the above options aren't working, then start looking at the internet, social media and public records. Each beneficiary will have different potential to have information in different locations, but it is a worthwhile place to look.

- Internet and Social Media
    - Google or other search engines. Search their name, known locations, obituary or death.
    - Social Media of the beneficiary on Facebook, Instagram, TikTok, Pinterest, etc.
    - Social Media of the contact or friends connected to the Beneficiary on Facebook, Instagram, TikTok, Pinterest, etc.
- Public Records
    - Property records: county appraisal or tax records; deed/property records;
    - Court Records: probate, guardianship, marriage, divorce, suits affecting the parent child relationship;
    - Voter registration (where publicly accessible);
    - Business filings or professional licenses;
    - Jail and prison searches or federal inmate locator; and
    - State death records.

Step 5 – Commercial Search, Private Investigators and other Creative Tools

Commercial search tools can be useful, but not all are available to find a person's location. Before using a commercial search product, understand what information the service provides and any restrictions on its use. Not every search product or source of consumer information can be used for every purpose. Some commercial search products and information may be subject to the Fair Credit Reporting Act (FCRA) or other restrictions. Make sure you understand the permissible uses before conducting the search.

- People Finder or White Pages;
- Ancestry.com to create a family tree and locate relatives;
- LexisNexis Accurint;
- CLEAR;
- TLOxp;
- TransUnion investigative tools;
- other permissible-purpose people-location products.

Step 6 – Death Search

If the trust believes the person to be deceased, then a death records search is necessary. Depending on your state and their vital statistics rules, you may be able

to get confirmation of death, such as a death verification letter, but not a death certificate.

- Social Security Death Master File;
- state vital statistics;
- obituaries;
- funeral homes;
- probate filings;
- county records;
- family;
- Medicaid estate recovery information;
- Funeral Insurance Plans or Trusts.

OTHER – Places that may have the information but won't give it to you.

There are plenty of organizations that MAY know where your beneficiary is but have no obligation—or legal ability—to give that information to you. That doesn't mean they are useless. Sometimes they can confirm limited information, forward a message, or provide another breadcrumb. What they can disclose will depend on the agency, applicable privacy laws, and your authority to receive the information. If you are listed as a representative, then they may, but otherwise they are probably roadblocks with some breadcrumbs.

- SSA, Medicaid, Banks, Hospitals, Doctors or IRS

Pooled trusts may consider working with some of these agencies, such as Medicaid or SSA, to create policies that allow pooled trust the ability to locate beneficiaries.

SEARCHING BUT HAVEN'T LOCATED

While you are searching for your beneficiary, you should continue to administer the trust as you do the rest of the pool. Reviewing all disbursements during this process is key.

1. Continue to administer the Trust with continued searches. Until you have confirmed the beneficiary's death or another legal basis to change the administration, the sub-account remains active. This generally includes continued investment management, administrative fees, tax administration and other appropriate trust administration.
2. Consider things that you SHOULD NOT continue to do
    a. Recurring payments and if they should continue. Look at what distributions are being sent out and if they are appropriate to continue regardless of the location of the beneficiary.

b. Consider pausing all discretionary distributions until correct contact information is obtained and the distribution can be confirmed that it is still for the benefit of the beneficiary.
c. Suspend or limit access to cards or other trust controlled funds until the beneficiary's circumstances are confirmed.

HOW LONG AND HOW MUCH TO SEARCH IS DUE DILIGENCE?

When looking for a beneficiary you must consider several factors when determining if due diligence is appropriate. Consider things like:

- account balance;
- length of time missing;
- beneficiary's circumstances;
- last known contact and available leads;
- cost of additional investigation;
- statutory obligations and trust provisions;
- likelihood beneficiary is deceased.

Depending on the governing trust document and applicable law, reasonable expenses incurred to locate the beneficiary may be an appropriate administrative expense of the sub-account or perhaps your retained fund. Review your trust document and policies before charging significant search, investigator or legal expenses to the account.

DOCUMENT

If you searched for them, document it. If you called someone, document it. If a search produced nothing, document that too. The question several years later should not be "Didn't somebody look for her?" Your records should show what was done, when it was done, what was found, and what the next step was.

Look at each stage above and document all the information gathered or not, contacts made and correspondence sent/received. Use your CRM/Database or other prescribed documentation method to track this information.

Consider your timeline and keep track of that as well.

Due diligence does not necessarily mean searching forever or spending thousands of dollars on every account. The scope of the search should be reasonable and proportionate to the circumstances.

WHEN TO HIRE A LAWYER

When considering hiring counsel to help locate a beneficiary, consider if there is a substantial account balance that warrants the cost of an attorney, if there is suspected death but no documentation, if there is a question as to whether distributions should stop, if there is proposed unclaimed-property treatment, court proceedings or questions involving access to protected records.

WHEN TO CONTACT APS OR LAW ENFORCEMENT

Most beneficiaries who cannot be located by the Trust are not "missing persons." But if the facts suggest exploitation, abuse, neglect, immediate danger, or an actual missing-person situation, the issue has moved beyond routine trust administration. Consider APS, law enforcement, counsel, or other appropriate authorities.

If you have a beneficiary who has gone no contact for a considerable amount of time and is usually communicating with the trust, think about what would be appropriate given the person, their disability, experience with law enforcement and their situation. This could be as simple as a welfare check or more involved. If contacting law enforcement, be sure to highlight anything that the authorities should know before interacting with the individual, such as a mental health, intellectual or developmental disability that may not be visible. Do not send law enforcement out without taking these things into consideration.

WHEN CAN WE FINALLY CLOSE THE ACCOUNT?

There is no one answer or one size fits all. The first step is to determine if the beneficiary is living-but-missing or deceased-but-unconfirmed. Before considering terminating the trust, look at the trust termination provisions to determine if that is an option or what that option would look like. Just because you haven't found them doesn't mean they are dead.

Review applicable state law concerning trust termination, unclaimed property, escheat and presumed death. In some states, the assets may remain held indefinitely.

Consult with an attorney and/or the court to determine if court involvement is appropriate and what guidance the court may give and/or order. This may include resignation as trustee, or the appointment of a successor trustee.

In a first party pooled trust, unresolved questions around retained funds provisions and Medicaid payback make consultation with an attorney especially important.

PREVENTION IS KEY - KEEPING UP WITH THE BENEFICIARY

Having a procedure to keep the trust informed of the beneficiary's contact information is key. This includes a preventative process. Gathering and keeping up to date as much information is imperative. Training and directing staff to update contact information as often as possible. This includes looking at invoices, amazon shipping locations, asking questions and confirming emails, phone numbers and addresses when speaking to a beneficiary.

Some things to consider:

1. At enrollment get as much information as possible.
    a. During enrollment, get not only the beneficiary and representatives information, consider asking for others who are in the lives of the person with a disability or even contacts who will know where the beneficiary is. (see Appendix A: The Arc of Texas Supplemental Information Form)
2. Reach out regularly to request contact updates.
    a. The Arc of Texas sends out an automated email through Salesforce once a year to our beneficiaries and/or representatives and attorneys through email to determine that their information is correct. It is sent 6 months after the beneficiary's birthday. The Arc of Texas sends out a Happy Birthday email to the beneficiary or their representative (depending on whose email is on file). Six months later we send an email with the current contact information and ask for any updates.
3. Create a returned mail procedure
    a. Ensure that returned mail is processed ASAP. Returned mail can often provide insight into the whereabouts of the beneficiary or their representative or if they or their representatives are alive. Often mail has information from the post office directly or someone who returns the mail directly. Look for notes in the automated forward or any handwritten indications on the returned envelope.
4. Pause requested discretionary disbursements until information is updated.
    a. Consider stopping certain recurring payments that have short term impacts. This will make someone reach out pretty quickly!

YOU'VE GOT THIS

Have a process. Search reasonably. Protect the beneficiary and the account. Document what you did. And know when the situation has become complicated enough to call counsel.



1

Staring
Haley D. Greer, JD
The Arc of Texas Master Pooled Trust

This presentation is brought to you in part by

2



The Disappearing Beneficiary

- ✓ Beneficiaries move, change providers, or lose contact without notifying the trust administrator.
- ✓ Many beneficiaries have a limited public footprint, and administrators may lose contact despite sending ongoing statements.

3

Why Finding Them Matters



Trustees Have:

- *Fiduciary Duties*
  Trustees must administer the trust responsibly, keep beneficiaries informed, and make reasonable efforts to locate missing beneficiaries to avoid liability.
- *Legal Obligations*
  Doing nothing may expose the trust to legal risk and breach of fiduciary duty.

Don't Forget:

- Duties vary by trust terms, state law, and applicable federal regulations governing special needs trusts.
- Reasonable search efforts protect both the beneficiary's interests and the trustee from liability.

4



Is the Beneficiary Actually Missing?

Quiet Beneficiary
- You have tried to reach out but they do not respond. No return mail or other indication that the person is not at their last known address. They continue to receive communication but do not respond. This does not mean they are or are not missing.

Unable to Contact
- They just may be hard to locate right now. These are the beneficiaries you know will reach out, but they only do so occasionally. You believe that they will reach out but don't have current contact information.

Whereabouts Unknown
- Attempts to locate have been made but no current location can be verified.

Status Unknown
- Cannot determine if this beneficiary is living or deceased.

5

Create A Search Protocol

Internal Records
- Database, Records, CRM

Direct Contact
- Reach out directly in every way possible

Beneficiary's Orbit
- Contact everyone in the Beneficiary's orbit. Former providers, landlords, attorney or other vendors.

Internet, Social Media, Public Records
- Internet and Social Media -Search Engine, Social Media, Social Media of the beneficiary's connections
- Public Records- Property records, court records and voter registration, jail and prison searches or state death records.

Commercial Search, Private Investigators and other Creative Tools
- People Finder or White Pages, Ancestry.com, LexisNexis Accurint, CLEAR, etc.

Death Records
- Make an official request at your state or local vital records office.



6



What To Do While You Search

- Continue to administer the Trust with continued searches.
- Consider things that you SHOULD NOT continue to do
  - Recurring payments and if they should continue.
  - Consider pausing all discretionary distributions
  - Suspend or limit access to cards or other trust controlled funds

7

DOCUMENT DOCUMENT DOCUMENT

Didn't someone look for her?

- If you searched for them, document it.
- If you called someone, document it.
- If a search produced nothing, document it

Asses how much effort is appropriate



8



When to Escalate

- Substantial account balance
- Disability and context
- Suspected undocumented death
- Uncertainty on disbursements
- Court or protected record access
- Hire Legal Counsel
- Contact APS
- Contact Law Enforcement

9

Closing the Account



Confirm Status

Verify whether the beneficiary is living or deceased before closing. Review trust terms, state law on termination, unclaimed property, and escheat rules.

Consult Counsel or Courts

Engage legal counsel or seek court guidance when closure involves disputed status, protected records, or complex trust termination requirements.

10



Prevention

Collect Contact Info

At enrollment, gather extensive contact details including emergency contacts, caregivers, and providers. Update regularly via email or phone check-ins.

Pause & Monitor Payments

Use returned mail as an early warning clue. Pause discretionary distributions when contact information is outdated or beneficiary location is unconfirmed.

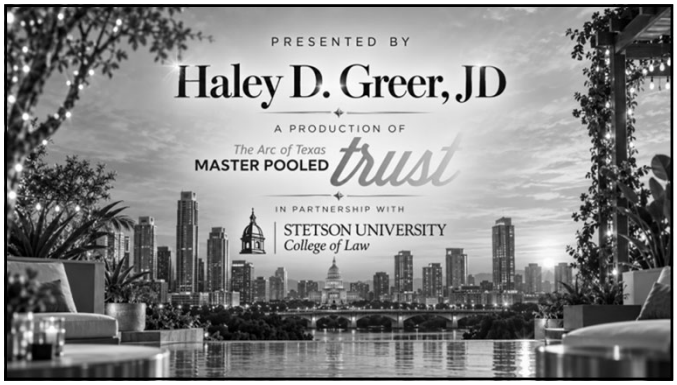
11

- Have a clear, documented search process in place
- Conduct reasonable, proportional searches based on account size and context
- Protect beneficiaries and trust assets at every stage
- Document all search actions thoroughly: dates, methods, findings
- Know when to seek expert help from legal counsel or APS



Best Practices

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PRESENTED BY
Haley D. Greer, JD
A PRODUCTION OF
The Arc of Texas
MASTER POOLED trust
IN PARTNERSHIP WITH
STETSON UNIVERSITY
College of Law

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STETSON LAW

Pooled Trusts Intensive

October 21, 2026

Benefits Counseling and Discretionary Distribution Decisions

STETSON LAW

Center for Elder Justice

Access and Justice For All®

Benefits Counseling and Discretionary Distribution Decisions

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Benefits Counseling and Discretionary Distribution Decisions

Overview: Benefits counseling and discretionary distribution decisions are distinct concepts, but often intersect in the administration of trusts, public benefits planning, and services for people with disabilities. Benefits counseling helps people with disabilities understand how employment, income, gifts, inheritances, settlements, or trust distributions may affect their eligibility for public benefits, allowing them to make informed financial decisions with confidence. For Trustees, benefits counseling provides significant value by aiding with discretionary distribution decisions, improving client outcomes, reducing the risk of unintended benefit loss, and strengthening relationships with beneficiaries, families, attorneys, and other professionals. In this program, we will discuss the “benefits” of benefits counseling for both beneficiaries and trustees, the type of benefits that should be covered, and how it can help a Trustee with discretionary decisions. Most importantly, how can your agency create their own benefits counseling team.

Benefits Counselor’s Can Provide:

- Work Incentives Guidance: Explains "work incentives", allowing work while receiving benefits.
- Informed Decision-Making: Empowers informed decisions about employment, education, and life choices.
- Financial Stability: Helps create a plan for financial stability and independence.
- Advice on Transition to Work: Helps understand how benefits are affected when returning to work.
- In essence, benefits counseling aims to remove the barriers and anxieties that disabled individuals may face when considering employment or making financial decisions.

AVAILABLE BENEFITS FOR PEOPLE WITH DISABILITIES

Social Security Disability Insurance (SSDI) - **Title II of the Social Security Act**, codified at 42 U.S.C. §§ 401–433. Social Security Disability Insurance (SSDI) federal regulations are governed by Title 20 of the Code of Federal Regulations (CFR), Part 404.

- Provides benefits to those who can't work due to a medical condition.
- Must have worked long enough and paid social security taxes.
- Inability to work must last at least a year or result in death.
- Benefits are based on the amount of money earned while working.
- Spouses and children of disabled workers can receive benefits.

Supplemental Security Income (SSI) - **Title XVI of the Social Security Act**, codified at 42 U.S.C. §§ 1381–1383f**.** Federal regulations for Supplemental Security Income (SSI) are codified under 20 CFR Part 416.

- Provides income to low-income individuals with disabilities.
- Must have limited income and resources.
- Aged, blind, and disabled people can qualify.
- Benefits are based on financial need.
- Work incentives may allow for continued benefits

Disabled Adult Child Benefits (DAC) or Childhood Disability Benefits (CDB) – **Title II of the Social Security Act,** codified at 42 U.S.C. § 402(d)). Federal regulations for these benefits are codified in the Code of Federal Regulations at 20 C.F.R. § 404.350.

- A child of a retired, disabled, or deceased parent may be eligible for benefits.
- The adult child must be unmarried and over 18.
- The child must have a disability that began before age 22.
- Benefits are based on the parent's earnings record.

Medicare - **Title XVIII of the Social Security Act**, codified at 42 U.S.C. § 1395 et seq. (Subchapter XVIII - Health Insurance for the Aged and Disabled). Medicare is a federal program primarily for the elderly and disabled, with eligibility based on age (65+) or having collected Social Security Disability Income (SSDI) for at least two years. There are no income or asset tests for Medicare itself, but there may be for assistance with premiums. It has four parts: Part A (hospital, hospice, home health care), Part B (physician services), Medicare Advantage (managed care), and Part D (prescription drugs).

Medicaid - **Title XIX of the Social Security Act**, codified at 42 U.S.C. § 1396 et seq. Specific core provisions include 42 U.S.C. § 1396a (State plans for medical assistance) and 42 U.S.C. § 1396d (Definitions), which outline federal guidelines, mandatory benefits, and state-federal cooperative requirements. Medicaid, also known as Medical Assistance (MA), is a joint state/federal program providing healthcare coverage for low-income individuals and children.

Eligibility is based on income and asset tests, and specific categories like SSI recipients, older adults, persons with disabilities, and others. Medicaid pays for a wide variety of services, including prescriptions and long-term care.

Medicaid vs. Medicare:

- **Medicare** is a federal program for elderly and disabled while **Medicaid** is a joint state/federal program for low-income individuals.
- **Medicare** eligibility based on age or disability while **Medicaid e**ligibility is based on income and assets.
- **Medicare** has no income/asset test while **Medicaid** has income/asset test required.

Other Federal Benefits for People with Disabilities

- Veterans Affairs (VA) disability benefits
- Veterans Pension
- Children's Health Insurance Program (CHIP)
- Supplemental Nutrition Assistance Program (SNAP)
- Temporary Assistance for Needy Families (TANF)
- Housing Choice Voucher Program (HCVP)
- Earned Income Tax Credit (EITC)

BENEFITS COUNSELING

- Benefits counseling helps individuals and businesses navigate complex benefit programs.
- Counselors help with benefit understanding, maximizing, and work incentive guidance for Social Security, Medicaid, Medicare and other benefits programs.
- For businesses, it provides marketing opportunities and reduces legal risks.
- Benefits counseling offers significant advantages for both individuals and businesses, particularly when navigating the complexities of social security, disability benefits, and related programs.

Who else might benefit from a Benefits Counseling program? Pooled Trusts

- Income stream: in some instances, there is the possibility of waiver payment
- Reduced Legal Risks: ensures compliance with disability-related laws for your beneficiaries
- Enhanced Social Responsibility: provides research for advocacy and advancement of mission
- Access to a broader talent pool: more diverse and inclusive workforce (hiring people who received counseling)
- Promotion and marketing: being an expert on benefits a trust is set to protect can give you a leg up in marketing your agency

Ways to Maximize a Benefits Counseling Program's Reach

- Partner with organizations serving people with disabilities.

- Offer educational workshops on trusts and estate planning.
- Create content that addresses benefits and trust services.
- Build relationships with relevant professionals like attorneys.
- Participate in community support events.
- Marketing
    - Attending industry conferences and events.
    - Offering continuing education courses.
    - Providing resources and support.
    - Web Content including Videos
    - Print Media/Advertising
    - Seminars and Speaking Engagements

<u>Building a BC Team</u>

Step One: Evaluate Current Needs. Assess the existing resources and gaps in services related to benefits counseling. Determine the size and scope of the team needed.

Step Two: Identify Necessary Expertise. Determine the specific skills and knowledge required for the team, such as expertise in SSDI, SSI, Medicare, Medicaid, and work incentives.

Step Three: Recruit and Hire Qualified Counselors. Look for individuals with experience in benefits counseling, social work, or related fields; or Train from Within. Provide opportunities for current employees to obtain benefits counseling certifications.

- Cornell University offers online certificate programs for professionals in the field of benefits counseling. These programs provide in depth knowledge on employee benefits. They also explore the role of the benefits counselor and relevant laws and regulations. Cornell currently offers a WIP-C, YOUTH-C, VET-C, and LEADERSHIP-C.
- Virginia Commonwealth University offers Certification CWIC and Community Partner Initial Training and Certification. The Community Work Incentives Coordinator (CWIC) and Community Partner Initial Training and Certification is designed for professionals who will deliver individualized work incentives counseling services to Social Security disability beneficiaries on a regular basis.

Step Four: Provide Training and Ongoing Education. Ensure that team members are knowledgeable about the latest regulations, policies, and best practices. Offer ongoing training opportunities to keep their skills up to date.

Step Five: Develop Standardized Procedures. Create clear guidelines and protocols for how counselors will interact with clients, provide information, and document their work. This should include efforts in organized record keeping.

Step Six: Establish Referral Networks. Build relationships with other organizations and professionals who serve individuals with disabilities, such as Area Agencies on Aging, Social Security offices, and vocational rehabilitation agencies as well as internal departments within your own organization.

Step Seven: Monitor and Evaluate Program Effectiveness. Track key metrics, such as the number of clients served and the outcomes of counseling sessions, to assess the team's performance and identify areas for improvement and areas and people not currently being served.

Step Eight: Secure Funding and Resources. Explore various funding sources, such as grants, contracts, and fee-for-service arrangements, to support the team's operations.

DISCRETIONARY DISTRIBUTIONS

Discretionary distributions from a pooled trust when someone receiving SSI, Medicaid, or other means-tested benefits, the key distinction is between money distributed directly to the beneficiary and the trust paying for something on the beneficiary's behalf. A trustee having **complete discretion over whether, when, and how much to distribute** does **not** by itself make distributions irrelevant to SSI. Social Security expressly distinguishes the status of the trust from the treatment of individual disbursements.

SSI - For a properly established pooled trust under **42 U.S.C. § 1396p(d)(4)(C)**, the trust itself can generally be excluded from the beneficiary's SSI resources. Federal law specifically recognizes pooled trusts as an exception to the ordinary trust-counting rules.

Distributions can still affect SSI per the Social Security Administration Rules:

Distribution	Typical SSI treatment
Cash paid directly to beneficiary	**Unearned income** in the month received
Money loaded onto beneficiary's debit card	Generally **unearned income**
Trust pays beneficiary's rent/mortgage	Can count as **in-kind support and maintenance (ISM)** and reduce SSI

Distribution	Typical SSI treatment
Trust pays for food	Since Sept. 30, 2024, food is no longer included in SSI ISM calculations
Trust pays medical expenses, education, therapy, recreation, telephone, etc. directly to a third party	Generally, **not income**
Trust buys an item that is an excluded resource	Generally, not income
Trust buys a non-excluded asset for the beneficiary	Can potentially be treated as income

For example: A pooled trust has $100,000 in the beneficiary's sub-account. The trustee has absolute discretion and decides to pay the beneficiary $500 in cash. The $100,000 may remain outside the beneficiary's countable SSI resources, **but the $500 cash distribution is generally $500 of unearned income for that month**. Conversely, if the trustee uses $500 to pay a therapist directly for services provided to the beneficiary, that payment generally isn't SSI income.

Medicaid - The federal pooled-trust exception is specifically part of the Medicaid trust statute, and states administer Medicaid under their own state rules within the federal framework. The pooled trust must meet statutory requirements, including separate beneficiary accounts, nonprofit management, and specified treatment of remaining funds at death.

The important questions are:

1. Is the pooled trust **first-party** (the beneficiary's own money) or **third-party**?

2. Is the person receiving **SSI, SSDI, Medicaid, or some combination**?
3. Will the distribution be **cash to the beneficiary**, or will the trustee pay a vendor directly?
4. What exactly is being purchased—**rent, food, medical care, transportation, education, a vehicle, etc.**?
5. What state is the beneficiary's Medicaid administered in?

How can a Benefits Counselor help with discretionary decisions?

Benefits Counselors are experts in the needs-based benefits and can assist with discretionary decisions that impact those benefits.

Benefits Counselors can also empower people with disabilities to make informed choices and plan for the future confidently.

Benefits counselors can use expertise to help make sense of various programs and understand rights, options, and responsibilities.

Benefits Counselors can deal with issues like overpayments errors, preventing costly mistakes, lead to advocacy on behalf of a person with a disability.

Benefits Counseling and Discretionary Distribution Decisions

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Family Trust
Protecting Futures. Enhancing Lives.

LeeAnn Fulena, Esquire

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Today's Agenda

- How does Benefits Counseling help people with disabilities?
- What types of Benefits are covered?
- Can a Benefits Counseling program benefit a Pooled Trust?
- How can Benefits Counseling help with Discretionary Distributions?
- Is there a good method to start a Benefits Counseling team?

2

Benefits Counseling Supports people with disabilities.



3

Whether you're dealing with financial, healthcare, or disability-related benefits, counseling can empower informed choices and plans for the future.



01

Clarity and Understanding: A benefits counselor help make sense of various programs. They ensure an understanding of rights, options, and responsibilities.

02

Reducing Stress and Uncertainty: Understanding how benefits interact—especially when experiencing changes in income—can ease the anxiety of making decisions.

03

Maximizing Benefits: A guide to optimizing benefits by identifying all the programs qualified for and helping avoid missed opportunities.

04

Problem Solving and Advocacy: Assists with benefit issues like overpayment errors, preventing costly mistakes, and advocacy on behalf of a person with a disability.

4

WORK!



5

Benefits Counselors Provide:

- Work Incentives Guidance: Explains "work incentives", allowing work while receiving benefits.
- Informed Decision-Making: Empowers informed decisions about employment, education, and life choices.
- Financial Stability: Helps create a plan for financial stability and independence.
- Advice on Transition to Work: Helps understand how benefits are affected when returning to work.
- In essence, benefits counseling aims to remove the barriers and anxieties that a person with a disability may face when considering employment or making financial decisions by giving the participant the tools and information to make an informed decision about employment, while highlighting the incentives and maximizing financial outcomes.
- **Employment comes with so much more than a paycheck - it comes with establishing routine, social connections and financial independence.**



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Benefits counselors can help with many different benefits.



7

Benefits for People with Disabilities

- Social Security Disability Insurance (SSDI)
- Supplemental Security Income (SSI)
- Medicare
- Medicaid
- Other Federal and State Benefits



8

Social Security Benefits

Supplemental Security Income

Disability Benefits

Disabled Adult Child Benefits

Survivor Benefits

Retirement Benefits



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Social Security Disability Insurance (SSDI)

- Provides benefits to those who can't work due to a medical condition.
- Must have worked long enough and paid social security taxes.
- Inability to work must last at least a year or result in death.
- Benefits are based on the amount of money earned while working.
- Spouses and children of disabled workers can receive benefits.



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Supplemental Security Income (SSI)

- Provides income to low-income individuals with disabilities.
- Must have limited income and resources.
- Aged, blind, and disabled people can qualify.
- Benefits are based on financial need.
- Work incentives may allow for continued benefits while working.

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Disabled Adult Child Benefits

- A child of a retired, disabled, or deceased parent may be eligible for benefits.
- The adult child must be unmarried and over 18.
- The child must have a disability that began before age 22.
- Benefits are based on the parent's earnings record.



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Social Security Retirement Benefits

- Provides income to retired workers and their families.
- Full retirement age varies depending on birth year.
- Benefits are based on earnings history.
- Spouses and dependents may also be eligible for benefits.



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Social Security Survivor Benefits

- Provides benefits for surviving spouses and children of deceased workers.
- One-time payment if they meet certain requirements.
- Monthly benefits based on deceased's earnings record.
- Must have worked long enough to qualify for benefits.

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Medicare and Medicaid

Medicare is a federal program primarily for the elderly and disabled with eligibility based on age (65+) or having collected Social Security Disability Income (SSDI) for at least two years.

There are no income or asset tests for Medicare itself, but there may be for assistance with premiums.

It has four parts: Part A (hospital, hospice, home health care), Part B (physician services), Medicare Advantage (managed care), and Part D (prescription drugs).

Medicaid, also known as Medical Assistance (MA), is a joint state/federal program providing healthcare coverage for low-income individuals and children.

Eligibility is based on income and asset tests, and specific categories like SSI recipients, older adults, persons with disabilities, and others.

Medicaid pays for a wide variety of services, including prescriptions and long-term care.

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Medicaid vs. Medicare

- **Medicare**: Federal program for elderly and disabled.
- **Medicaid**: Joint state/federal program for low-income individuals.

- **Medicare**: Eligibility based on age or disability.
- **Medicaid**: Eligibility based on income and assets.

- **Medicare**: No income/asset test.
- **Medicaid**: Income/asset test required.

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Other Federal Benefits for People with Disabilities



- Veterans Affairs (VA) disability benefits
- Veterans Pension
- Children's Health Insurance Program (CHIP)
- Supplemental Nutrition Assistance Program (SNAP)
- Temporary Assistance for Needy Families (TANF)
- Housing Choice Voucher Program (HCVP)
- Earned Income Tax Credit (EITC)

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Pooled Trusts Can Benefit from Benefits Counseling programs



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How Can It Help?

- Reduced Legal Risks: ensures compliance with disability-related laws for your beneficiaries
- Enhanced Social Responsibility: provides research for advocacy and advancement of mission
- Access to a broader talent pool: more diverse and inclusive workforce (hiring people who received counseling)
- Promotion and marketing: being an expert on benefits a trust is set to protect can give you a leg up in marketing your agency



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Ways to Maximize a Benefits Counseling Program's Reach

- Partner with organizations serving people with disabilities.
- Offer educational workshops on trusts and estate planning.
- Create content that addresses benefits and trust services.
- Build relationships with relevant professionals like attorneys.
- Participate in community support events.



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Demonstrating expertise and providing valuable resources, trust companies can build credibility and attract clients who are seeking comprehensive financial solutions.

Potential Marketing Opportunities:

- **Estate Planning and Beneficiary Support:**
  - Benefits counselors often work with individuals and families facing complex financial situations.
    - Providing guidance on managing inherited assets by the use of trusts.
    - Assisting with financial planning and budgeting.
    - Helping beneficiaries understand their rights and responsibilities.
- **Financial Wellness Programs:**
  - By incorporating information on government benefits and how they interact with financial planning, trust companies can attract clients who are seeking comprehensive financial guidance.
- **Building Relationships with Professionals:**
  - Benefits counselors often work closely with other professionals, such as attorneys, social workers, and financial planners.
    - Attending industry conferences and events.
    - Offering continuing education courses.
    - Providing resources and support.

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Web Content including Videos



Print Media/Advertising

Seminars and Speaking Engagements



How We Market Our Program

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Benefits Counseling Overview

- Benefits counseling helps individuals and trustees navigate complex benefit programs.
- Counselors help with benefit understanding, maximizing, and work incentive guidance for Social Security, Medicaid, Medicare and other benefits programs.
- For Trustees, it provides marketing opportunities and reduces legal risks.

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Benefits Counseling can aid with Discretionary Distributions



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Discretionary Distributions

- Key distinction when someone receives means-tested benefits (such as SSI or Medicaid) is between money paid directly to the beneficiary and the trust paying for something on their behalf.



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- A trustee having complete discretion over whether, when and how much to distribute to a beneficiary does not by itself make distributions irrelevant to SSI.
- Social Security expressly distinguishes the status of the trust from the treatment of individual disbursements
- The properly established Pooled Trust itself can generally be excluded from the beneficiary's SSI resources.
- Federal law specifically recognizes a pooled trust as an exception to any ordinary trust-counting rules.
- However, Distributions can still affect SSI per Social Security Administration Rules.

SSI

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Typical SSI Treatment

Distribution	Typical SSI treatment
Cash paid directly to beneficiary	Unearned income in the month received
Money loaded onto beneficiary's debit card	Generally, unearned income
Trust pays beneficiary's rent/mortgage	Can count as in-kind support and maintenance (ISM) and reduce SSI
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Distributions can still affect SSI per the Social Security Administration Rules

Examples

- A pooled trust has $100,000 in the beneficiary's sub-account. The trustee has absolute discretion and decides to pay the beneficiary $500 in cash. The $100,000 may remain outside the beneficiary's countable SSI resources, **but the $500 cash distribution is generally $500 of unearned income for that month**.
- Conversely, if the trustee uses $500 to pay a therapist directly for services provided to the beneficiary, that payment generally isn't SSI income.

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Medicaid

- The federal pooled-trust exception is specifically part of the Medicaid trust statute, and states administer Medicaid under their own state rules within the federal framework.
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The important questions are:

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3. Will the distribution be **cash to the beneficiary** or will the trustee pay a vendor directly?
4. What exactly is being purchased—**rent, food, medical care, transportation, education, a vehicle, etc.**?
5. In what state is the beneficiary's Medicaid administered?

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How can a Benefits Counselor help with Discretionary Decisions?

- Benefits Counselors are experts in needs-based benefits and can assist with discretionary decisions that impact those benefits.
- Benefits Counselors can also empower people with disabilities to make informed choices and plan for the future confidently.
- Benefits counselors can use expertise to help make sense of various programs and understand rights, options, and responsibilities.
- Benefits Counselors can deal with issues like overpayment errors, preventing costly mistakes and lead to advocacy on behalf of a person with a disability.

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How To Create a Benefits Counseling Team



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Steps to Building a BC Team

Step One: **Evaluate Current Needs.** Assess the existing resources and gaps in services related to benefits counseling. Determine the size and scope of the team needed.

Step Two: **Identify Necessary Expertise.** Determine the specific skills and knowledge required for the team, such as expertise in SSDI, SSI, Medicare, Medicaid, and work incentives.

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Steps to Building a BC Team

Step Three: **Recruit and Hire Qualified Counselors.** Look for individuals with experience in benefits counseling, social work, or related fields; or

Train from Within. Provide opportunities for current employees to obtain benefits counseling certifications.

Step Four: **Provide Training and Ongoing Education.** Ensure that team members are knowledgeable about the latest regulations, policies, and best practices. Offer ongoing training opportunities to keep their skills up to date.

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Steps to Building a BC Team

Step Five: **Develop Standardized Procedures.** Create clear guidelines and protocols for how counselors will interact with clients, provide information, and document their work. This should include efforts in organized record keeping.

Step Six: **Establish Referral Networks.** Build relationships with other organizations and professionals who serve individuals with disabilities, such as Area Agencies on Aging, Social Security offices, and vocational rehabilitation agencies as well as internal departments within your own organization.

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Steps to Building a BC Team

Step Seven: **Monitor and Evaluate Program Effectiveness.** Track key metrics, such as the number of clients served and the outcomes of counseling sessions, to assess the team's performance and identify areas for improvement and areas and people not currently being served.

Step Eight: **Secure Funding and Resources.** Explore various funding sources, such as grants, contracts, and fee-for-service arrangements, to support the team's operations.

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Cornell Benefits Certification



- Cornell University offers online certificate programs for professionals in the field of benefits counseling.
- These programs provide in depth knowledge on employee benefits.
- They also explore the role of the benefits counselor and relevant laws and regulations.
- Cornell currently offers a WIP-C, YOUTH-C, VET-C, and LEADERSHIP-C.

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Virginia Commonwealth University Certification

CWIC and Community Partner Initial Training and Certification

The Community Work Incentives Coordinator (CWIC) and Community Partner Initial Training and Certification are designed for professionals who will deliver individualized work incentives counseling services to Social Security disability beneficiaries on a regular basis.

Work incentive counseling is the delivery of in-depth advisement to Social Security disability beneficiaries about the effect of an earning goal on their public benefits, including Social Security disability benefits, Medicaid, Medicare, and other public benefits.

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Benefits counseling offers significant advantages for both individuals and trustees, particularly when navigating the complexities of Social Security, disability benefits, and related programs.

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Any Questions?

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Thank you for your attention.



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October 21, 2026

Social Security and SSI Update 2026 (The Ken & Jen Show)

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National Conference on
Special Needs Planning and Special Needs Trusts
Pooled Trust Intensive Preconference

2026 Social Security and Supplemental Security Income (SSI) Program Update

Presented by Ken Brown and
Jennifer Burdick
October 21, 2026

STETSON UNIVERSITY

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ACCESS AND JUSTICE FOR ALL®

2026 Social Security and Supplemental Security Income (SSI) Program Update

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Social Security and SSI Update 2026

TRUMP ACCOUNTS

Introduction

A Trump Account (TA) is a tax-advantaged investment account established for children. A type of traditional Individual Retirement Account (IRA), TAs have special rules that change depending on the TA beneficiary's age. TAs have two primary periods:

- Growth period, which begins with the establishment of the initial TA and ends on December 31 of the calendar year in which the TA beneficiary attains age 17; and
- Post-growth period, which is effective January 1 of the calendar year in which a TA beneficiary attains age 18 and continues thereafter.

TAs are established for the benefit of children and may be funded with first-party and third-party contributions. The parent, guardian, or other authorized individual who completes an election form to open a TA is generally the responsible party and account custodian for the Trump account. Generally, in 2026, up to $5,000 (adjusted for inflation) can be contributed per year per child, and contributions are invested in low-cost index funds. A TA beneficiary may only have one TA funded at a time.

Every US citizen born between January 1, 2025 and December 31, 2028 is eligible for a one-time $1,000 government seed contribution if the account is established before the year they turn 18. This contribution does not count toward the annual $5,000 contribution limit.

Annual Contribution Limits and Who Can Contribute

- $5,000 per year total per child (indexed for inflation after 2027).
- Anyone can contribute: parents, guardians, family, friends and even the child when older.
- Employers can contribute up to $2,500 per year for an employee’s dependent child, excluded from the employee’s taxable income.
- Charities and government entities may also contribute to groups of eligible children, sometimes without counting toward the $5,000 annual limit.

How are These Accounts Invested?

- The accounts during the “growth period” (period prior to the beneficiary turning 18) are limited to investing in mutual funds/ETFs that track to a qualified index with at least 90 percent US company weighting (e.g., S&P 500), do not use leverage and

have annual fees/expenses below 0.1 percent. Cash and money market funds are not permitted.
- The intention of this rule is to encourage long-term market exposure and compound growth rather than short-term trading.
- This long-term investing structure, paired with consistent funding and compound returns, gives these accounts significant growth potential over many years.
- Trump Accounts will initially be created and held with Treasury's designated financial agent. Eventually, parents or guardians should be able to transfer the full balance to a preferred brokerage firm through a trustee-to-trustee rollover.

Growth Period

Prior to January 1 of the year the TA beneficiary attains age 18 (growth period):

- The entire value of a TA is not considered a resource for SSI purposes.
- Distributions from the TA generally are not permitted. The following do not count as distributions:
    - a rollover to another TA during the growth period;
    - a rollover to an ABLE account when permitted during the calendar year of age 17 attainment (referred to in this section as the "Age 17 TA-ABLE rollover");
    - removal of excess contributions over the annual limit; and
    - distributions upon the death of the TA beneficiary.
- Contributions made directly to the account are generally not considered income; however, a TA beneficiary cannot avoid income counting by direct depositing funds into a TA. For example, a TA beneficiary could not have their Social Security benefits direct deposited into a TA to prevent them from counting as unearned Social Security income for SSI purposes.

  NOTE: A beneficiary or recipient with a representative payee cannot have their Social Security or SSI payments paid via direct deposit into a TA during the growth period when distributions generally are not permitted. Due to TA distribution restrictions, the representative payee generally would not be able to use the benefits to provide for the beneficiary's current needs.

Post-Growth Period

Beginning January 1 of the calendar year the TA beneficiary attains age 18 (post-growth period):

- The TA is a countable resource. The value of the TA is the amount of money that the TA beneficiary can withdraw from the TA after any penalty for early withdrawal (i.e., early distribution tax).
- Distributions of TA funds are not income, but a conversion of a resource.

- Contributions to a TA are income or a conversion of a resource, depending on the source of the contribution.

  For instance:

  - If a TA beneficiary transfers money from their savings account into their TA, the contribution is a conversion of a resource, changing form from a financial institution account resource to a TA resource.

    Example: On 1/15/27, a TA beneficiary transfers $500 of existing account funds from their savings account to their TA. For SSI purposes, on 1/1/27, $500 is counted as a financial account resource. On 2/1/27, $450 is counted as a TA resource ($500-10% early withdrawal penalty=$450).

  - If a TA beneficiary's parent deposits a $1,000 "graduation gift" into the TA, the $1,000 is unearned income in the month of deposit.
  - If a TA beneficiary direct deposits $200 of their paychecks into their TA, each $200 deposit is earned income in the month of deposit.

  Contributions are a countable TA resource beginning the following month.

Age 17 TA - ABLE rollovers

During the calendar year a TA beneficiary attains age 17, TAs are eligible for the age 17 ABLE rollover. Through a trustee-to-trustee transfer, the entire balance of the TA may be rolled over to an ABLE account for the TA beneficiary. The rollover is an exception to TA distribution rules and ABLE contribution limits.

Through the TA-ABLE rollover, the TA, which is considered an asset that is not a resource for SSI purposes, is transferred to an ABLE account. Up to $100,000 in an ABLE account may be excluded from resource counting. The TA beneficiary does not receive countable income as a result of this transaction.

Important: All TA funds that are not rolled over to ABLE accounts during this period will become countable TA resources effective January 1 of the following year (i.e., the year in which the TA beneficiary attains age 18).

SSA AND ARTIFICIAL INTELLIGENCE (AI)

Introduction

SSA has acknowledged the transforming potential of AI. It aspires to “amplify the potential of AI while protecting sensitive data and mitigating the associated risks and limitations.” SSA, Enterprise Artificial Strategy Report, 2025.

Where's SSA in its AI journey? SSA released its *Enterprise Artificial Intelligence Strategy Report* in late 2025. In it, SSA reported that SSA is at a level 2 out of 5 on its AI Maturity Assessment. Id. At. 3. A level 2 is defined as "Established-Some processes are planned and executed in accordance with policy but are in early stages of development. Processes are not used across all organizational areas." SSA is targeting an AI maturity of 3 by the end of 2026 and fur by the end of 2030.

SSA is obligated to disclose its AI projects on an AI inventory. Expert Dave Wittenburg analyzed SSA's list of current and upcoming AI tools, summarizing: "SSA's AI inventory suggests a portfolio shaped by operational fragmentation rather than a single unified AI architecture. The agency's highest-impact tools remain concentrated in benefits processing and disability adjudication, where classical predictive models support triage, review, prioritization, and quality control. At the same time, generative AI is spreading across policy search, vocational analysis, coding, training, HR, customer service, and internal productivity. Taken together, the inventory shows AI being used as a bridge across legacy systems, document-heavy workflows, and dispersed policy/data assets. The pattern is not simply fragmented AI; it is AI being layered onto a fragmented operating environment, with governance and documentation varying substantially by risk level and business function."

In the Enterprise Report, SSA described where it hopes to go and its strategic focus areas that are driving SSA's future implementation of AI. To expand AI use, SSA reports it needs to standardize its processes, follow them, and tailor them to broader needs. Because SSA's legacy system is so outdated, SSA's AI focus also involves targeting "inhibitors to successful AI implementation."

How will it do that? SSA has an AI Governance Board to provide leadership and oversight while ensuring AI priorities align with SSA's goals. This board is tasked, among other things, to make decisions on "high-risk use cases." SSA also has a Responsible AI Core Team that drafts and communicates governance standard for AI and provides assistance and advice on use cases. Enterprise Report at 9. SSA warned that to accomplish their objectives, they would need Role Based AI-training across the organization. Notably, SSA explained:

"The proliferation of AI tools at SSA will be complimented by our customer service agents and front-line employees learning how to extract the most value from these tools while remaining aware of their limitations for the customer service experience. Leaders need to be aware of the capabilities and limitations of various AI tools and users need to understand when, where, and how to apply them. The agency will identify both online self-paced and in-person AI training to upskill employees in technical, managerial, and AI user

roles. A culture that embraces AI fluency is essential to accomplish our AI vision." Enterprise Report at 5.

What AI is Being Used for Now?

- **AI & Phones:**

SSA launched a new telecom platform with expanded self-service initiatives. As of February 2026, SSA reported reduced wait times (to 8 minutes) as a result. Additionally, SSA reports that 75% of inquiries are now resolved/addressed via automation, according to Press Officer Barton Mackey. Id.

Some of the changes around SSA's phone answering service is due to the implementation of AI. **SSA's FY 2025-2026 plan** indicated they were going to use AI tools to improve the interactive voice response and push the chatbot which was built from SSA's website FAQs.

- **AI and Adjudication:**

SSA is using AI in its disability adjudications. The AI adjudication tool that SSA has discussed publicly the most is IMAGEN (Intelligent Medical Language Analysis Generation). IMAGEN is now being used in Disability Determination Services across the country. This tool is described to be is like Instagram for medical evidence. It converts all the records into a format that can be searched and analyzed. DDS adjudicators use this in order to search records for key words. IMAGEN will also flag when is it is 80% likely someone will meet a listing and highlight the evidence where it finds the support.

Another tool is HeaRT (Hearing Recording and Transcription). This tool was rolled out in March 2025 described a "modernizing the hearing transcription process." This system uses AI to create more accurate automated transcripts.

A predictive modelling tool called Quick Disability Determination (QDD), is being used to screen initial applications to find cases where there is a high likelihood of a favorable determination.

SSA also rolled out the VAAT (Vocational Assessment Assistance Tool) in late 2025 or early 2026. This is an AI tool developed by SSA designed to assist DDS examiners during Steps 4 and 5 in the sequential evaluation, to answer questions of whether a particular claimant can return to their past work (step 4) or do any other competitive, full-time work in the country (step 5). This tool was intended to help adjudicators find the most accurate DOT codes for past work and complete a transferable skills analysis. It also helps identify if there are appropriate medical-vocational rules that apply (GRIDS).

Based on reports, this was rolled out as a mandatory tool for adjudicators to use in early 2026, but SSA quickly backtracked to say the tool must be used with caution after significant errors surfaced.

More is likely to come. In August 2026, SSA solicited feedback on an enterprise artificial strategy via a Request for Information. In it, SSA indicated they are seeking information on model's, case studies, and approaches that agencies or industry have taken on AI use cases. They are also seeking approaches to attract and onboard people with AI skills. They are also seeking information on training and governance.

Notably: Advocates have raised some concerns about SSA's use of AI. In particular, the National Academy of Social Insurances (NASI)'s AI Task Force issued a report in April 2025. It highlights the real risk on using AI for right-impacting disability benefit. It encourages SSA to focus its AI use on system that assist instead of replace decisionmakers.

ACCESSORY DWELLING UNITS

Introduction

An "Accessory Dwelling Unit" or "ADU" is defined by the American Planning Association as "a smaller, independent residential dwelling unit located on the same lot as a stand-alone (i.e., detached) single-family home." *Accessory Dwelling Units*, American Planning Association, (Retrieved September 22, 2026). ADUs can be converted portions of existing homes (i.e., internal ADUs), additions to new or existing homes (i.e., attached ADUs), or new stand-alone accessory structures or converted portions of existing stand-alone accessory structures (i.e., detached ADUs).

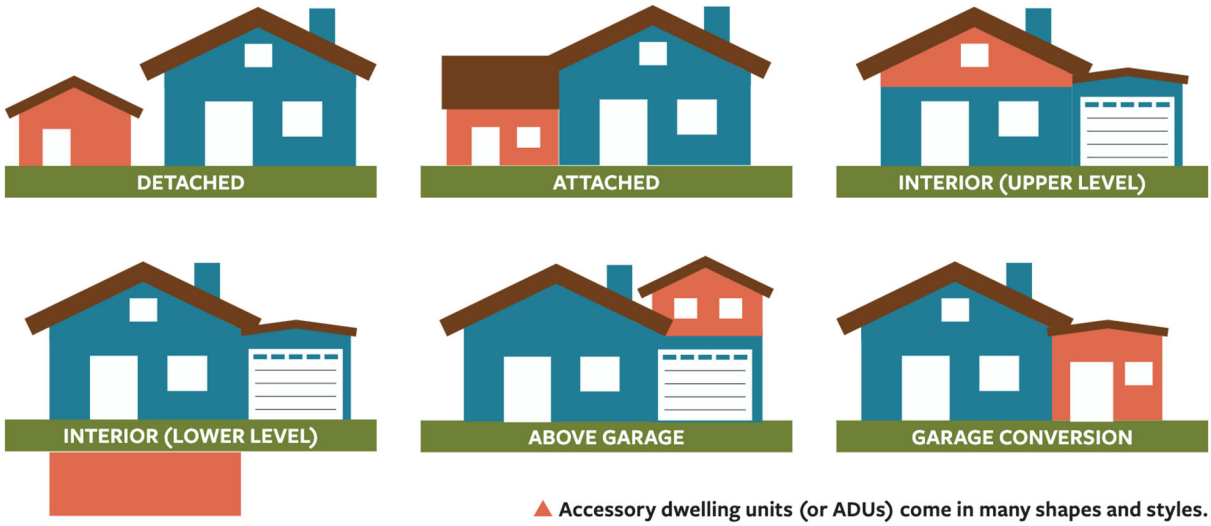
Although most government regulations, zoning laws and urban planners refer to them as accessory dwelling units, ADUs have been around for decades (or centuries) and have been referred to by various names:

- accessory apartment
- backyard bungalow
- basement apartment
- casita
- carriage house
- coach house
- English basement
- garage apartment
- granny flat
- guest cottage

- guest house
- in-law suite
- multi-generational house
- ohana unit
- secondary dwelling unit

Generally, as an independent living space, an ADU is self-contained, with its own kitchen or kitchenette, bathroom and sleeping area. However, an attached ADU may share kitchen or bathroom facilities with the main dwelling unit (depending on local zoning requirements).

Once commonplace, after World War II, many local governments placed restrictions on or prohibited the construction of ADUs. With the advent of the housing affordability problem, many local, city, county and even State governments are relaxing restrictions on and encouraging the use of ADUs and even requiring communities to allow them.



▲ Accessory dwelling units (or ADUs) come in many shapes and styles.

The ABCs of ADUs, AARP (last visited September 23, 2026).

OWNERSHIP ISSUES RELATED TO ACCESSORY DWELLING UNITS

Ownership issues related to Accessory Dwelling Units (ADUs) often arise because the ADU is located on the same parcel as the primary home, creating questions about property rights, control, financing, and inheritance. Common issues include:

Single Property Ownership

In many jurisdictions, an ADU cannot be sold separately from the primary residence because both structures share one legal lot. The homeowner owns both the main house and the ADU. This can create complications when family members or a trust contribute money to build an ADU but do not receive a legal ownership interest.

Co-Ownership and Family Arrangements

When parents, adult children, other relatives, or a trust help finance or occupy an ADU, disputes can arise over:

- Who owns the ADU structure.
- Rights to occupy the unit.
- Responsibility for maintenance and repairs.
- What happens if the property is sold.

Without a written agreement, these arrangements can become contentious.

Title and Financing Concerns

Because the ADU is usually part of the same real estate parcel:

- It generally cannot have a separate deed.
- Mortgages and liens typically affect both the main house and the ADU.
- Lenders may require all owners of the property to sign financing documents.

Inheritance and Estate Planning

If an ADU is intended for a child or elderly parent, problems may arise after the property owner's death:

- The ADU may pass with the entire property under a will or state inheritance laws.
- Occupants of the ADU may not automatically gain ownership rights.
- Heirs may disagree about whether to keep, occupy, rent, or sell the property.

Estate planning can help clarify these issues.

Zoning, Land Use and Property Rights Disputes

Ownership conflicts can arise when:

- Neighbors challenge ADU construction.
- Property boundaries are unclear.

- Easements or access rights affect the ADU.
- Owners disagree about use restrictions or rental rights.
- Zoning restrictions on and requirements of rental units or owner-occupancy requirements.

WHY OWNERSHIP MATTERS FOR SSI BENEFITS

Home Exclusion

Regardless of its physical form, legally an ADU is part of the same property as the main home. It cannot be bought or sold separately, as a condominium or a dwelling on wheels might be. The owner of the ADU is the owner of the main home. To qualify for the home exclusion, an individual must have an ownership interest, legal or equitable, in the home. You should note however, that without an ownership interest, a home would not count as a resource to the individual, but there are other consequences that flow from not having an ownership interest.

ISM

Without an ownership interest, the individual would be required to pay rent or else be charged with in-kind support and maintenance (ISM) in the form of rent-free shelter. Or they could be subject to the value of the one-third reduction (VTR) in their benefits because they are residing in the household of another.

Paying rent or shelter costs is not a bad thing in and of itself, but if the goal is to maximize benefits, paying rent and expenses or incurring a reduction for ISM is a step in the wrong direction.

If there is a rental situation, it is likely that there may be a parent-child relationship between the landlord and the tenant (anyone in the household is a parent or child of the landlord or landlord's spouse). In that case, rental subsidy (where the tenant is not paying CMRV (current market rental value)) may be an issue. However, a recent regulatory change now provides that effective 09/30/2024, a business arrangement exists when the monthly required rent (including a flat fee payment) equals or exceeds the PMV ($351.33 for an individual and $517.00 for an eligible couple in 2026). If the verified monthly required rent equals or exceeds either the CMRV or the PMV, no rental subsidy applies. If the monthly required rent is less than both the CMRV and the PMV, the amount of rental subsidy is determined by subtracting the monthly required rent from the CMRV or PMV, whichever is less.

Trust Management

If a trust is paying for the construction of an ADU for the use of the trust beneficiary, the trustee may feel it is necessary, in its fiduciary duty, for the trust to obtain an interest in the ADU. The following options would provide the beneficiary a place to live for life, give the trust a legal or equitable interest in the ADU for its payments and not benefit a non-beneficial interest, at least not immediately.

POSSIBLE SOLUTIONS FOR THE OWNERSHIP ISSUE

Equitable Ownership

As previously discussed, an "equitable" ownership interest in property can result from personal considerations or from:

- making mortgage payments;
- making or paying for additions to a shelter; or
- making improvements to a shelter.

If an individual alleges an unwritten equitable ownership interest, SSA will gather all the necessary information and forward it to the Regional Chief Counsel for an opinion based on State law.

Condominium or Separate Ownership Structures

Some states and local governments allow legal mechanisms, such as condominiumization or lot splits, that can create separate ownership interests for an ADU. However, such situations are currently very rare and availability varies significantly by jurisdiction. Local zoning and property laws determine whether separate ownership is allowed.

In most cities and towns, there's a preferred way to create separate ownership of homes: the subdivision process. But what if there's a desire to separate ownership and subdivision isn't an option?

This situation arises most often when (1) properties are on top of one another as described previously in multi-story buildings, or (2) land use regulations make it difficult or impossible to subdivide property horizontally (i.e., minimum lot sizes can't be met; subdivision regulations that preclude a desired site layout; there's no way to provide every lot required street frontage). For these instances, use of condominium ownership to separate ownership is the only choice. Conveniently, all 50 states and the District of Columbia have adopted condominium statutes that allow property to be converted to condominium ownership and back again, if desired. The power and appeal of the

condominium legal structure is to offer a way to separate ownership between units in settings where subdivision doesn't work. Legally, condominiums are 'creatures of the state,' meaning that their existence depends on state laws that lay out the rules for their creation, maintenance, and dissolution. Each condominium project contains a group of housing units, defined by a map ('the 'Plat') and narrative description (found within the 'Declaration'). Condo unit owners each own a defined volume of air plus an undivided interest in the shared elements of the condominium property (called "General Common Elements") as drawn on the Plat and defined in the Declaration. These typically include the underlying land and any structures or parts of structures that need to be maintained by the association rather than by individual unit owners. In traditional multi-story buildings, the common elements include the underlying land and the building's foundation, structural elements, insulation, common utility lines, windows & doors, roof and siding. Individual units are usually defined to include the volume of air 'from the paint in' or some other appropriate demarking surface. ADUs and Condos: Separating Ownership, Accessory Dwellings (Retrieved September 23, 2026).

Condominiumization and subsequent transfer of ownership to the trust would provide the trust beneficiary a home for as long as they wanted or need it and legal ownership of the ADU by the trust.

Condominium conversion most often makes sense in a commercial situation where the ADU will be sold as a separate unit or in a rental situation rather than in a family-occupied ADU since the legal costs involved may reach several tens of thousands of dollars.

Life Estate

One possible avenue that could be explored – as I could not find any examples where it had been used before – is the use of a partial life estate. I say "partial" life estate since both the primary house and the ADU are part of the same deed and property, and a regular life estate would give the tenant use of and rights to the entire property. A partial life estate can legally apply to a specific portion or acreage of a larger piece of real estate (such as an ADU) rather than the entire property.

When you create a partial life estate, you split the legal ownership and use rights for just a designated section of land or a specific structure (such as a house while leaving surrounding acreage out, or vice versa). It can apply to a specific floor, a guest house, or a defined acreage of a larger farm.

The deed or trust must explicitly describe the specific portion assigned to the life tenant. It requires an accurate, legally sound survey and distinct legal description of the specific portion attached to the deed.

How a Partial Life Estate Works

- The Life Tenant: Obtains the exclusive right to use, occupy, or collect income from that specific part of the property for the rest of their life.
- The Remainderman: Holds the future interest to inherit that exact portion of the property automatically when the life tenant passes away, and, if the remainderman is not the original grantor, bypassing probate.

Duties like taxes and maintenance are typically prorated or assigned based on the terms of the agreement.

Key Advantages

- Targeted Inheritance**:** Directs a specific house, cabin, or section of land to a chosen heir, unless it returns to the grantor.
- Probate Avoidance: Transfers the designated portion automatically to the remainderman upon death.
- Continued Control: Guarantees the life tenant a secure place to live or use during their lifetime without interference.

Critical Risks & Limitations

- Subdivision Restrictions: Local zoning laws, county ordinances, or HOA rules may may legally restrict dividing a single residential structure or lot.
- Shared Control: Depending on whether it is with or without "powers," you may need the remainderman's signature to sell, mortgage, or alter the designated portion later.
- Practical conflicts: Sharing access to utilities, land, or common areas can create friction between the life tenant and the remainderman.
- Maintenance & Taxes: The life tenant remains legally responsible for taxes, insurance, and upkeep on the property, which can get complicated if only a sub-portion is metes-and-bounds defined.

If a trust is paying for the construction of an ADU for the use of the trust beneficiary, the trustee may feel it is necessary, in its fiduciary duty, for the trust to obtain an interest in the ADU. Naming the trust as the life estate grantee would provide the beneficiary a place to live for life, give the trust a legal interest in the ADU for its payments and not benefit a non-beneficial interest, at least not immediately.

A FEW NOTES ON TINY HOUSES

A thorough discussion of tiny houses could take a session in itself because of the wide variety of structures that could qualify as tiny houses. This would include both fixed-site and mobile varieties.

There is some variation in defining a tiny home, but there are examples and they are usually based on floorspace. The International Residential Code states that a tiny house's floorspace is no larger than 400 square feet (37 m^2). Merriam-Webster says they can be up to 500 ft^2. One architectural firm used a threshold of 600 ft^2 to define a tiny home. What further complicates the definition is that tiny homes may or may not be mobile and lack clearly defined features.

The tiny home movement started in the late 1990s has grown through the 2020s. The movement's core involves living full-time in a very small floorspace building. In some cases, tiny houses are very small houses with a foundation, plot, and traditional sewage and electrical hookups, while in other cases, they are more mobile, like an RV or mobile home. Types of tiny houses include shipping container homes, small houseboats, bus conversions, and more. Tiny House Movement, Wikipedia (Retrieved September 23, 2026).

One of the biggest obstacles faced by the tiny-house movement is the difficulty of finding a region in which such a house can be constructed. Zoning regulations typically specify minimum square footage for new constructions on a foundation, and for tiny houses on wheels, parking on one's own land may be prohibited by local regulations against camping. Prohibitions may also extend to mobile homes, RVs, or temporary structures. Many localities do not allow these forms as legal dwellings, primarily due to concerns over stability, sanitation, and permanence.

In addition, RV parks do not always allow tiny houses unless they meet the criteria required for RVs. Tiny houses on wheels are considered RVs and are not suitable for permanent residence, according to the Recreational Vehicle Industry Association (RVIA). From *RV Business,* "The RVIA will continue to shy away from allowing members who produce products that are referred to as 'tiny houses' or 'tiny homes.' Vail, K. (2016). "Saving the American Dream: The Legalization of the Tiny House Movement". *University of Louisville Law Review*, 54(2), 357–379.

In general, SSA should consider any tiny house built on a foundation with utility hookups as real property, the same as it would consider an ADU or other full-sized house and the same policy considerations would apply.

Considering a mobile tiny house (which would be considered as personal property), for purposes of the home exclusion, a home can be real or personal property, fixed or mobile, and located on land or water. For purposes of excluding “the land on which the shelter is located,” it is not necessary that the individual own the shelter itself.

EXAMPLE: If an individual lives on their own land in someone else's trailer, the land meets the definition of a home and is excluded. However, if the individual does not own the shelter, it is necessary to consider whether the shelter results in in-kind support and maintenance (ISM) (e.g., rent-free shelter).

Use of Land

The use of land alone is not a household cost. Thus, if an individual receives land or the use of land without charge, this does not result in outside ISM. Similarly, third party vendor payments of real property tax, rent or mortgage on land alone do not cause an individual to receive ISM in the form of shelter.

A trailer space rental fee which is for space alone is not a household operating expense for purposes of determining inside ISM, nor is it outside ISM if someone outside the household pays the fee. However, if the fee is not for use of land alone, that part of the fee which is for water, sewer, etc., is part of the household costs for purposes of determining inside and outside ISM.

EXAMPLE: James Smith, an eligible individual, lives alone in a house trailer they own. The trailer is situated on the property of their sibling, Bill. James pays no rent for the use of the land. Bill provides water and electricity free of charge. The free use of the land results in no ISM to James. However, James is charged with outside ISM based on the CMV of the water and electricity.

NOTE: The use of land without charge may result from the individual holding an easement, a life estate, or a similar arrangement. If so, resource development of the arrangement may be necessary. POMS, SI 00835.465D.4.

POOLED TRUST MANAGEMENT PROVISIONS

THE TRUST MUST BE ESTABLISHED AND MANAGED BY A NON-PROFIT ASSOCIATION

PS 01825.002 Alaska (08/19)

D. PS 19-097 Analysis of whether the J~ Irrevocable Asset Trust, which is established by Alaska's Office of Public Advocacy, qualifies as a pooled trust under 42 U.S.C. § 1396p(d)(4)(C)

This Regional Chief Counsel (RCC) opinion examines whether a pooled trust sub-account qualifies as a pooled trust under 42 U.S.C. § 1396p(d)(4)(C) and POMS SI 01120.203.D. The RCC concludes that it does and therefore must be evaluated under

POMS SI 01120.200 to determine if it is a countable resource for Supplemental Security Income (SSI) purposes.

PS 01825.017 Indiana (05-18)

E. PS 18-085 Review of the Southwestern Indiana Regional Council on Aging, Inc. Pooled Trust

This Regional Chief Counsel (RCC) opinion examines whether sub-accounts in the Southwestern Indiana Regional Council on Aging, Inc. Pooled Trust for Disabled Persons (Trust) comply with the requirements for a pooled trust exception under section 1917(d)(4)(C) of the Social Security Act (Act). The RCC concludes that a self-funded sub-account in the Trust would be considered a resource because it does not meet all of the requirements. However, a third party-funded sub-account in the Trust would not be considered a resource under our regular policy for third party trusts as resources in POMS SI 01120.200D.

PS 01825.037 North Dakota - TN 173 (02-20)

A. PS 20-223 Lutheran Social Service of Minnesota's North Dakota Self-Settled Pooled Trust

This Regional Chief Counsel (RCC) opinion examines whether the Lutheran Social Service of Minnesota's North Dakota Self-Settled Pooled Trust ("Trust") and Joinder Agreement comply with the requirements for a pooled trust exception under section 1917(d)(4)(C) of the Social Security Act (Act). In a previous opinion (PS 18-102), the RCC concluded that the Trust allows for the Trust Fund Manager (potentially a for-profit entity) to have excess managerial authority. Further, the Joinder Agreement does not conform to the Trust Agreement. These defects were cured effective with an August 1, 2019 amendment and the trust now satisfies the requirements of the pooled trust exception. In addition, and unlike the Joinder Agreement previously reviewed, the revised Joinder Agreement appears to properly conform to the Amended Trust.

B. PS 18-102 Lutheran Social Service of Minnesota's North Dakota Self-Settled Pooled Trust (06-18)

This Regional Chief Counsel (RCC) opinion examines whether the Lutheran Social Service of Minnesota's North Dakota Self-Settled Pooled Trust ("Trust") and Joinder Agreement comply with the requirements for a pooled trust exception under section 1917(d)(4)(C) of the Social Security Act (Act). The RCC concludes that the Trust allows for the Trust Fund Manager (potentially a for-profit entity) to have excess managerial

authority. Further, the Joinder Agreement does not conform to the Trust Agreement. Therefore, the Trust does not meet the pooled trust exception, and trust sub-accounts are countable resources.

PS 01825.049 Utah TN 186 (05-20)

A. PS 20-031 Secured Futures Pooled Special Needs Trust & the Utah Amendment, March 23, 2020

This Regional Chief Counsel opinion examines whether the Secured Futures Pooled Special Needs Trust (the "Trust") and Joinder Agreement, and Utah Amendment thereto, satisfy the pooled trust exception at 42 U.S.C. § 1396p(d)(4)(C). The opinion concludes that the Trust does not meet the pooled trust exception to counting assets in the Trust sub-accounts as resources because it impermissibly allows the Trustee to delegate responsibilities to a for-profit entity that must be retained by the Trustee.

PS 01825.055 Wisconsin (03-19)

D. PS 19-079 Review of Life Navigators, Inc. Amended Master Trust Agreement for Trust II Pooled Trust

This Regional Chief Counsel (RCC) opinion examines whether the second-amended version of the Life Navigators, Inc. Master Trust Agreement for Trust II pooled trust (we evaluated the first-amended version under "PS 17-062 Review of Life Navigators, Inc. Master Trust Agreement for Trust II Pooled Trust" below in this section) now satisfies the criteria for the pooled trust exception under section 1917(d)(4)(C) of the Social Security Act. The RCC concludes that the second-amended version now meets all of the requirements of the pooled trust exception, and sub-accounts in the pooled trust would not be considered resources for SSI purposes.

Successor Trustees and Co-Trustees

PS 01825.025 Michigan (07-19)

I. CPM 19-094 Review of the Michigan Arc Pooled Amenities Trust and Joinder Agreement

This Regional Chief Counsel (RCC) opinion examines whether the master trust declaration for the Arc Michigan Pooled Amenities Trust and the Joinder Agreement for NH D~ are in compliance with SSA's pooled trust policy. The RCC concludes that the trust does not comply with SSA's pooled trust policy. Specifically, the trust allows for a successor trustee that is not a non-profit organization; it allows the trustee to use funds

in sub-accounts to cover the costs of actions affecting only other sub-accounts; and the trust appears to allow for someone other than the individual, a court or the individual's parent, grandparents, or legal guardian to establish a sub-account in the trust with the assets of the disabled individual.

PS 01825.025 Michigan

E. PS 20-035 Review of the Second Amendment and Restatement to the Pooled Accounts Trust of the Arc of Midland, April 2, 2020

In this opinion the Regional Chief Counsel (RCC) examines the second amended and restated Declaration of Trust for the Pooled Accounts Trust of the Arc of Midland to determine whether it complies with the procedures governing the Agency's pooled trust policy. The RCC concludes that the Trust does not meet all of the requirements of the pooled trust exception. Specifically, the Trust allows for execution of core managerial duties by a for-profit entity, sub-accounts containing funds for multiple beneficiaries, and the use of a beneficiary's funds for the benefit of another beneficiary.

PS 01825.039 Ohio

G. CPM 19-087 Review of The Ohio Community Pooled Annuity Master Trust (06-19)

In this opinion, the Regional Chief Counsel (RCC) examines whether the Ohio Community Pooled Annuity Master Trust (Trust), as amended in 2014, is in compliance with SSA's pooled trust policy. The RCC concludes that the trust does not comply with pooled trust policy because it allows the non-profit entity to delegate control of core management functions to a for-profit organization. Therefore, self-settled funds in accounts established by a disabled individual on or after January 1, 2000, would be resources. Because this trust was previously determined to be excepted from resource counting, a 90-day amendment period applies.

H. CPM-19-077 Review of The 2014 Ohio Community Pooled Flexible-Spending Trust (05-19)

In this opinion, the Regional Chief Counsel (RCC) examines whether the 2014 Ohio Community Pooled Flexible-Spending Trust meets the criteria for the pooled trust exception. The trust does not comply with pooled trust policy because it allows the non-profit entity to delegate control of core management functions outside the non-profit organization. Accounts in the Trust would be considered resources under the Social Security Act.

PS 01825.017 Indiana TN 200 (09-20)

B. PS 20-076 The New Leaf National Foundation Special Needs Pooled Trust, August 11, 2020

In this opinion the RCC examines the Leaf National Foundation Special Needs Pooled Trust to determine if it complies with agency pooled trust policy. Due to problematic language concerning the management of the pooled trusts, which could allow management functions to fall to for-profit entities, the trust does not meet the pooled trust exception for self-settled trusts under 42 U.S.C. § 1396p(d)(4)(C).

PS 01825.025 Michigan (11-20)

D. PS 20-097 Review of the Third Amendment and Restatement to the Pooled Accounts Trust of the Arc of Midland

In this opinion, the Regional Chief Counsel (RCC) examines the Third Amendment and Restatement to the Pooled Accounts Trust of the Arc of Midland to determine whether it complies with the procedures governing the Agency's pooled trust policy. The RCC concludes that while the amendment cures deficiencies found in prior versions, the Trust still does not meet all of the requirements of the pooled trust exception. Specifically, the Trust allows a for-profit entity serving as a substitute Trustee to execute core managerial duties. Third-party sub-accounts in the Trust and third-party assets in a commingled sub-account would not be considered a resource under the Agency's regular resource rules.

APPENDICES

APPENDIX A

Program Operations Manual System (POMS)

Effective Dates: 07/09/2026 - Present TN 105 (07-26)

SI 01120.250 Trump Accounts (TAs)

Public Law No. 119-21, Sec. 70204; Sec. 530A of the Internal Revenue Code; Social Security Act, Sec. 1613

A. Overview of TAs

A Trump Account (TA) is a tax-advantaged investment account established for children. A type of traditional Individual Retirement Account (IRA), TAs have special rules that change depending on the TA beneficiary's age. TAs have two primary periods:

- Growth period, which begins with the establishment of the initial TA and ends on December 31 of the calendar year in which the TA beneficiary attains age 17; and
- Post-growth period, which is effective January 1 of the calendar year in which a TA beneficiary attains age 18 and continues thereafter.

TAs are established for the benefit of children and may be funded with first-party and third-party contributions. The parent, guardian, or other authorized individual who completes an election form to open a TA is generally the responsible party and account custodian for the Trump account. Generally, in 2026, up to $5,000 (adjusted for inflation) can be contributed per year per child, and contributions are invested in low-cost index funds. A TA beneficiary may only have one TA funded at a time. A federal pilot program provides a $1,000 contribution to the TAs of eligible children born between January 1, 2025, and December 31, 2028. More information on TAs is available at trumpaccounts.gov.

B. Policy for the income and resource treatment of TAs

The income and resource treatment of TAs changes based on the age of the TA beneficiary.

1. Growth Period

Prior to January 1 of the year the TA beneficiary attains age 18 (growth period):

- The entire value of a TA is not considered a resource for SSI purposes.
- Distributions from the TA generally are not permitted. The following do not count as distributions:
    - a rollover to another TA during the growth period;
    - a rollover to an ABLE account when permitted during the calendar year of age 17 attainment (referred to in this section as the "Age 17 TA-ABLE rollover");
    - removal of excess contributions over the annual limit; and
    - distributions upon the death of the TA beneficiary.
- Contributions made directly to the account are generally not considered income; however, a TA beneficiary cannot avoid income counting by direct depositing funds into a TA. For example, a TA beneficiary could not have their Social Security benefits direct

deposited into a TA to prevent them from counting as unearned Social Security income for SSI purposes.

NOTE: A beneficiary or recipient with a representative payee cannot have their Social Security or SSI payments paid via direct deposit into a TA during the growth period when distributions generally are not permitted. Due to TA distribution restrictions, the representative payee generally would not be able to use the benefits to provide for the beneficiary's current needs (see GN 00602.001A.2).

For processing instructions during the growth period, see SI 01120.250C in this section.

For additional information on the Age 17 TA-ABLE rollover, see SI 01120.250C.3 in this section.

2. Post-Growth Period

Beginning January 1 of the calendar year the TA beneficiary attains age 18 (post-growth period):

- The TA is a countable resource. The value of the TA is the amount of money that the TA beneficiary can withdraw from the TA after any penalty for early withdrawal (i.e., early distribution tax).

- Distributions of TA funds are not income, but a conversion of a resource.

- Contributions to a TA are income or a conversion of a resource, depending on the source of the contribution.

  For instance:

  - If a TA beneficiary transfers money from their savings account into their TA, the contribution is a conversion of a resource, changing form from a financial institution account resource to a TA resource.

    Example: On 1/15/27, a TA beneficiary transfers $500 of existing account funds from their savings account to their TA. For SSI purposes, on 1/1/27, $500 is counted as a financial account resource. On 2/1/27, $450 is counted as a TA resource ($500-10% early withdrawal penalty=$450).

  - If a TA beneficiary's parent deposits a $1,000 "graduation gift" into the TA, the $1,000 is unearned income in the month of deposit.
  - If a TA beneficiary direct deposits $200 of their paychecks into their TA, each $200 deposit is earned income in the month of deposit.

  Contributions are a countable TA resource beginning the following month.

For processing instructions during the post-growth period, see SI 01120.250D in this section.

C. Development and documentation of TAs during growth period (initial TA establishment through December 31 of the calendar year in which the TA beneficiary attains age 17)

1. Initial claims, redeterminations (RZs), and post-eligibility reports of change for children under age 16

When evaluating resources during initial claims, RZs, and post-eligibility events for SSI applicants or recipients under age 16:

- Accept the parent, guardian, or payee's allegations regarding whether a TA has been established for the child and the estimated account value.

- Record the allegation on an "Other Resources" page by selecting "Trump Account (TA)" from the "Type" drop-down menu. In the "Description" field, include the name of the alleged account custodian (i.e., the "responsible party"), the financial institution administering the account, and the account number if known. See MS 08113.032 for more information on the Other Resources page.

  NOTE: Account custodians are not co-owners; the account beneficiary owns the TA and funds.

- Enter the entire "Alleged Value" in the "Excluded Amount" field. Use exclusion reason "Trump account (TA)."

- From the Direct SSR Update Menu (UMEN), select "Diaries," and manually post an RT diary on the Update Diaries (UDIA) screen. Set the maturity date for January 1 of the calendar year the child will attain age 17.

- Input the following SSR remarks, "RT - [insert maturity date 1/1/xx] Age 17 TA/ABLE Rollover development."

2. Special development for TA-related RT diaries reaching maturity and for claims, RZs, or resource-related post-eligibility contacts for SSI applicants and recipients aged 16 and 17.

Complete development in SI 01120.250C.2.a through SI 01120.250C.2.d during:

- RZs related to the maturation of a TA-related RT diary; and/or
- claims, RZs, or resource-related post-eligibility contacts for claimants aged 16 or 17.

a. Request evidence of TA ownership and balance

To develop or update TA information:

- Screen for a TA or changes to a TA.

- Request statements, account records, or other evidence of TA ownership and account value. Store evidence electronically using the Evidence Portal.

- Document the TA (or update a previously documented TA) on the “Other Resources” page by selecting “Trump Account (TA)” from the "Type" drop-down box.

- Enter the entire “Alleged Value” in the "Excluded Amount" field. Use exclusion reason “Trump account (TA).”

b. Inform the TA beneficiary and custodian about post-growth period resource counting and the TA-ABLE rollover option

- Advise the individual that TA funds will become countable effective January 1 of the year the TA beneficiary attains age 18.

- Explain the TA - ABLE rollover, which is available during the calendar year a TA beneficiary attains age 17, as discussed in SI 01120.250C.3 in this section. If more information is requested, direct them to the Spotlight On Achieving A Better Life Experience (ABLE) Accounts | Supplemental Security Income (SSI) | SSA.

c. Post an Age 18 RT diary to redevelop TA resources prior to the December Goldberg-Kelly (GK) cutoff.

- From the Direct SSR Update Menu (UMEN), select "Diaries," and manually post an RT diary on the Update Diaries (UDIA) screen to redevelop the TA and potential TA-ABLE rollover. Set the maturity date for December 1 of the calendar year the child attains age 17.

- Add the following SSR remarks, “RT - [insert maturity date 12/1/xx] Age 18 develop TA/ABLE Rollover and remove TA exclusion effective 1/1/[insert calendar year of age-18 attainment].”

d. Redevelop TA and potential TA - ABLE rollover and post the countable TA value when the Age 18 RT diary matures.

Prior to the GK cutoff in December of the same year (i.e., the year in which the TA beneficiary attains age 17), when the Age 18 RT diary matures, check for a potential TA-ABLE rollover.

- If rollover is alleged, process according to SI 01120.250C.3 in this section.

- If rollover is not alleged, redevelop the TA value, and remove the TA resource exclusion effective January 1 of the following year (i.e., the year in which the TA beneficiary attains age 18). If the payee fails to provide information necessary for determining continuing eligibility, see SI 02301.235.

See SI 01120.250D in this section for more instructions on processing TAs in the post-growth period.

3. Age 17 TA - ABLE rollovers

a. Overview of Age 17 TA - ABLE rollovers

During the calendar year a TA beneficiary attains age 17, TAs are eligible for the age 17 ABLE rollover. Through a trustee-to-trustee transfer, the entire balance of the TA may be rolled over to an ABLE account for the TA beneficiary. The rollover is an exception to TA distribution rules and ABLE contribution limits.

Through the TA-ABLE rollover, the TA, which is considered an asset that is not a resource for SSI purposes, is transferred to an ABLE account. Up to $100,000 in an ABLE account may be excluded from resource counting. The TA beneficiary does not receive countable income as a result of this transaction. See SI 01130.740 for more information on ABLE accounts.

Important: All TA funds that are not rolled over to ABLE accounts during this period will become countable TA resources effective January 1 of the following year (i.e., the year in which the TA beneficiary attains age 18).

b. Development and documentation of Age 17 TA - ABLE rollovers

If a TA beneficiary or account custodian alleges a rollover of the TA to an ABLE account:

- Request evidence that the rollover has been completed (e.g., TA account statement showing zero balance or account closure and ABLE state exchange data or ABLE account statements). Store evidence electronically using the Evidence Portal, as applicable.
- Update the “Other Resources/TA” and “ABLE account” pages to reflect the resource status changes.
- Delete the Age 18 RT diary and SSR remarks indicating the need for TA redevelopment.
- Follow the procedures in SI 01130.740 to develop ABLE account exclusions.

D. Development and documentation of TAs in the post-growth period (beginning January 1 of the calendar year in which the TA beneficiary attains age 18.)

While developing TA resources for months beginning January 1 of the calendar year in which the TA beneficiary attains age 18 and thereafter:

- Develop TA ownership, account value, and distributions, as applicable. Obtain evidence following normal resource verification policies in SI 01140.010.

- Develop for contributions to the TA. If the TA beneficiary alleges or evidence indicates contributions to a TA, determine whether the contributions are income or conversions of a resource and document the contributions according to normal policies (e.g., SI 00810.010, SI 01110.600).

- When an individual alleges resource values that preclude SSI eligibility, accept the allegation following SI 01140.010B.2.a.

- Count the value of TAs (i.e., the amount that the TA beneficiary can withdraw after any penalty for early withdrawal), unless the account can be excluded under another policy (e.g., an approved Plan to Achieve Self-Support, SI 00870.001).

  NOTE: Penalties for early withdrawal for a given year are available on the IRS website, where they are referred to as "additional tax for early withdrawal." The penalty tax is the same for TAs and traditional IRAs.

- Record TAs (or update previously developed TAs) on an “Other Resources” page under the type “Trump Account (TA).” See MS 08113.032 for more information on the Other Resources page.

  NOTE: Ensure the growth-period TA resource exclusion has been removed effective January 1 of the calendar year the TA beneficiary attains age 18.

- Store account statements or other evidence in the electronic folder using the Evidence Portal.

If the recipient or payee fails to provide information necessary for determining continuing eligibility, see SI 02301.235.

E. Examples of TA development

1. Young child qualifying for the pilot program contribution

In a 7/10/26 initial application for a disabled child born 10/1/25, the CS learns from the child’s mother that she made a TA election for the child when she filed her taxes, listing herself as the “responsible party” who would oversee the account. No contributions have been made, but she alleges the government is putting $1,000 into the account through the pilot program. The CS lists the TA on the “Other Resources” page, notes the mother as the account custodian in the description, and then posts the $1,000 alleged balance to the "Excluded Amount" field in July 2026 and continuing with the exclusion reason “TA.” The CS adds an RT diary to the record with a maturity date of 010142. The CS annotates in the SSR remarks field “RT-01/01/42 Age 17 TA/ABLE Rollover development.”

2. Special development during routine redetermination for a 16-year-old child

During a 5/1/27 redetermination for a disabled child born 4/3/2011, the CS learns the child's father established a TA for the child during the 2026 tax season. The father alleges an account value around $1,500. He contributed $500 when he opened the account, and the child's grandmother contributed $1,000 in December 2026. Because the child is 16 and special development applies, the CS informs the father that the child's TA balance will become accessible, and therefore a countable resource for SSI purposes, on 1/1/29. The CS informs the father that the TA could be rolled over into an ABLE account between 1/1/2028 and 12/31/2028 and provides the link to the ABLE Spotlight for more information. The CS requests evidence of the TA and its value and requests that the father report if an ABLE rollover is pursued.

Before closing the redetermination event, the CS completes the "Other Resources/TA" page using information from a current TA account statement, listing account details in the "Description" field, and posting the current account value in the "Excluded Amount" field with the exclusion reason "TA." The CS adds an RT diary with a maturity date of 120128 and annotates the SSR remarks field with "RT – 12/01/28 Age 18 develop TA/ABLE Rollover and remove TA exclusion effective 01/01/29."

3. Post-Growth period TA development

The CS contacts the father from example 2 at the end of November 2028 to resolve the maturing Age 18 RT diary. During the review, the father reports that an ABLE account wasn't opened. The CS obtains an updated account statement for the TA, which shows a current balance of $1,720. The CS screens for resource exclusions, and, after finding none, advises the father that the funds would be a countable resource for the child beginning January 2029 and continuing. On the TA resource page, the CS calculates the early withdrawal penalty (10% of 1720=172; 1720-172=1548) and updates the verified resource value of $1,548 for December 2028. For January 2029 and continuing, the CS posts $1,548 as the alleged resource value, ensures the alleged account balance is removed in the "Excluded amount" field, and stores the TA account statement in Evidence Portal.

F. References

SI 00810.010 Relationship of Income to Resources

SI 01110.100: Distinction Between Assets and Resources

SI 01110.600: First-of-the-Month (FOM) Rule for Making Resource Determinations

SI 01130.740 Achieving a Better Life Experience (ABLE) Accounts

SI 01140.010 Resource Verification Requirements

SI 01150.007 Transfer of Resources by Spenddown

APPENDIX B

CRS REPORT – Trump Accounts: Overview and Policy Considerations, Congressional Research Service, Library of Congress

APPENDIX C

Program Operations Manual System (POMS)

Effective Dates: 04/03/2012 - Present TN 86 (05-24)

SI 01120.225 Pooled Trusts Management Provisions

CITATIONS:

Social Security Act (Act) as amended, Section

1917(d)(4)(C)(42 U.S.C. § 1396p(d)(4)(C))

A. How to determine when to apply the policies in this section

1. New trusts and trusts that have not been previously excepted under section 1917(d)(4)(A) or (C) of the Act

A trust that is either newly formed or not previously excepted from resource counting must meet all of the criteria set forth in SI 01120.199 through SI 01120.203 and SI 01120.225 through SI 01120.227 to be excepted under section 1917(d)(4)(A) or (C). Do not except such a trust from resource counting unless the trust meets all of these requirements.

2. Trusts that previously met the requirements to be excepted under section 1917(d)(4)(A) or (C) of the Act

A trust that was previously determined to be excepted from resource counting under section 1917(d)(4)(A) or (C) continues to be excepted from resource counting, provided the trust is amended to conform with the requirements of this section within 90 days. That 90-day period begins on the day the recipient or representative payee is informed that the trust contains provisions that must be amended in order to continue qualifying for the exception under section 1917(d)(4)(A) or (C). Do not count a previously excepted trust as a resource during the 90-day amendment period.

If the trust still fails to meet the requirements of this section after the expiration of the 90-day amendment period, begin counting the trust under normal resource counting rules.

NOTE: Each previously excepted trust is permitted only one 90-day amendment period.

B. Background of pooled trusts management

To qualify for exception under the provisions of section 1917(d)(4)(C), a pooled trust must be managed by a non-profit association. By law, each trust beneficiary must have a separate account, but the non-profit manager can pool these funds with the funds of other members of this communal trust. In some instances, the non-profit manager(s) may employ the services of a for-profit entity to manage some of the financial activities of the trust.

C. Case processing alert

Trusts are often complex legal arrangements involving State law and legal principles that a claims representative may not be able to apply without obtaining the advice of legal counsel. Therefore, the following instructions may only be sufficient to recognize that an issue is present that you should refer to the regional office (RO) for possible referral to the Office of Program Law. When in doubt, discuss the issue with the RO staff. You can resolve many issues by phone.

D. Policy on use of for-profit entities

If a non-profit association employs the services of a for-profit entity, the non-profit association must maintain ultimate managerial control over the trust. The for-profit entity may handle certain trust functions on behalf of the non-profit association; however, the use of a for-profit entity must always be subordinate to the non-profit managers of a pooled trust under section 1917(d)(4)(C).

For example, the non-profit association must be responsible for:

- determining the amount of the trust corpus to invest;
- removing or replacing the trustee; and
- making the day-to-day decisions regarding the health and well-being of the pooled trust beneficiaries.

NOTE: This list is not intended to be exhaustive. These are a few examples of the type of authority that must vest in the non-profit association.

E. Procedure for determining management control of the pooled trusts

Do not routinely question the relationship between the non-profit association and for-profit entities used by the pooled trust.

However, before excepting a pooled trust under section 1917(d)(4)(C), review the trust for any provisions that indicate the non-profit association has not retained sufficient authority over the pooled trust to meet the criteria in section 1917(d)(4)(C).

For example, a pooled trust may not meet the criteria in section 1917(d)(4)(C) if the trust includes a provision that allows the for-profit entity to determine whether to make discretionary disbursements from the trust.

Refer the pooled trust document to the regional office for evaluation if it appears that the non-profit organization may not have sufficient control over the management of the trust for the trust to be excepted under section 1917(d)(4)(C).

STETSON LAW

2026 National Conference on Special Needs Planning and Special Needs Trusts

Pooled Trust Intensive Preconference

2026 Social Security and Supplemental Security Income (SSI) Program Update

Presented by Ken Brown
and
Jennifer Burdick
October 21, 2026

STETSON UNIVERSITY
Center for Excellence in Elder Law
Access and Justice For All
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Outline of Today's Presentation

- Trump Accounts
- SSA and Artificial Intelligence
- Accessory Dwelling Units (ADUs)
- Pooled Trust Management Provisions

1

1

Trump Accounts

A Trump Account (TA) is a tax-advantaged investment account established for children by P.L. 119-21. A type of traditional Individual Retirement Account (IRA), TAs have special rules that change depending on the TA beneficiary's age. TAs have two primary periods:

- Growth period, which begins with the establishment of the initial TA and ends on December 31 of the calendar year in which the TA beneficiary attains age 17; and
- Post-growth period, which is effective January 1 of the calendar year in which a TA beneficiary attains age 18 and continues thereafter.

2

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Annual Contribution Limits and Who Can Contribute

- Starting July 4, 2026, $5,000 per year total per child (indexed for inflation after 2027).
- Anyone can contribute: parents, guardians, family, friends and even the child when older.
- Employers can contribute up to $2,500 per year for an employee's dependent child, excluded from the employee's taxable income.
- Charities and government entities may also contribute to groups of eligible children, sometimes without counting toward the $5,000 annual limit.
- Every US citizen born between January 1, 2025 and December 31, 2028 is eligible for a one-time $1,000 government seed contribution if the account is established before the year they turn 18. This contribution does not count toward the annual $5,000 contribution limit.

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How are These Accounts Invested?

The accounts during the "growth period" (period prior to the beneficiary turning 18) are limited to investing in:

- mutual funds/ETFs that track to a qualified index with at least 90 percent US company weighting (e.g., S&P 500),
- do not use leverage, and
- have annual fees/expenses below 0.1 percent.

Cash and money market funds are not permitted.

Trump Accounts will initially be created and held with Treasury's designated financial agent. Eventually, parents or guardians should be able to transfer the full balance to a preferred brokerage firm through a trustee-to-trustee rollover.

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Growth Period

Prior to January 1 of the year the TA beneficiary attains age 18 (growth period):

- The entire value of a TA is not considered a resource for SSI purposes.
- Distributions from the TA generally are not permitted. The following do not count as distributions:
  - a rollover to another TA during the growth period;
  - a rollover to an ABLE account when permitted during the calendar year of age 17 attainment (referred to in this section as the "Age 17 TA-ABLE rollover");
  - removal of excess contributions over the annual limit; and
  - distributions upon the death of the TA beneficiary.

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Growth Period

Contributions made directly to the account are generally not considered income; however, a TA beneficiary cannot avoid income counting by direct depositing funds into a TA.

For example, a TA beneficiary could not have their Social Security benefits direct deposited into a TA to prevent them from counting as unearned Social Security income for SSI purposes.

NOTE: A beneficiary or recipient with a representative payee cannot have their Social Security or SSI payments paid via direct deposit into a TA during the growth period when distributions generally are not permitted. Due to TA distribution restrictions, the representative payee generally would not be able to use the benefits to provide for the beneficiary's current needs.

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Post-Growth Period

Beginning January 1 of the calendar year the TA beneficiary attains age 18 (post-growth period):

- The TA is a countable resource. The value of the TA is the amount of money that the TA beneficiary can withdraw from the TA after any penalty for early withdrawal (i.e., early distribution tax).
- Distributions of TA funds are not income, but a conversion of a resource.

7

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Post-Growth Period

Contributions to a TA are income or a conversion of a resource, depending on the source of the contribution.

- For instance: If a TA beneficiary transfers money from their savings account into their TA, the contribution is a conversion of a resource, changing form from a financial institution account resource to a TA resource.
- If a TA beneficiary's parent deposits a $1,000 "graduation gift" into the TA, the $1,000 is unearned income in the month of deposit.
- If a TA beneficiary direct deposits $200 of their paychecks into their TA, each $200 deposit is earned income in the month of deposit.

Contributions are a countable TA resource beginning the following month.

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Age 17 TA - ABLE Rollovers

- During the calendar year a TA beneficiary attains age 17, TAs are eligible for the age 17 ABLE rollover. Through a trustee-to-trustee transfer, the entire balance of the TA may be rolled over to an ABLE account for the TA beneficiary. The rollover is an exception to TA distribution rules and ABLE contribution limits.
- Up to $100,000 in an ABLE account may be excluded from resource counting.
- Important: All TA funds that are not rolled over to ABLE accounts during this period will become countable TA resources effective January 1 of the following year (i.e., the year in which the TA beneficiary attains age 18).

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SSA and Artificial Intelligence (AI) A Balancing Act

SSA aspires to "amplify the potential of AI while protecting sensitive data and mitigating the associated risks and limitations ."

Enterprise Artificial Strategy Report

10

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SSA and AI - A Balancing Act

The National Association of Social Insurance (NASI) AI Task Force warns that there are significant risks for SSA to use AI in a rights-impacting context, and gave SSA guidance and guardrails for how to carefully evaluate AI risks and opportunities in this context.

NASI, AI Taskforce Phase One Report

11

11

Where is SSA Now?

- SSA reports its AI maturity to be a 2 out of 5.
- A level 2 is defined as "Established - Some processes are planned and executed in accordance with policy but are in early stages of development. Processes are not used across all organizational areas."
- SSA is targeting an AI maturity of 3 by the end of 2026 and 4 by the end of 2030.

12

12

How is AI Used Now?

- AI & Phones: SSA is using AI tools in the interactive voice response chatbox
- HeaRT (Hearing Recording and Transcription), rolled out in March 2025
- IMAGEN (Intelligent Medical Language Analysis Generation)
- QDD (Quick Disability Determination)
- VAAT (Vocational Assessment Assistance Tool)

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Accessory Dwelling Units (ADUs)

An "Accessory Dwelling Unit" or "ADU" is defined by the American Planning Association as "a smaller, independent residential dwelling unit located on the same lot as a stand-alone (i.e., detached) single-family home."

Generally, as an independent living space, an ADU is self-contained, with its own kitchen or kitchenette, bathroom and sleeping area. However, an attached ADU may share kitchen or bathroom facilities with the main dwelling unit (depending on local zoning requirements).

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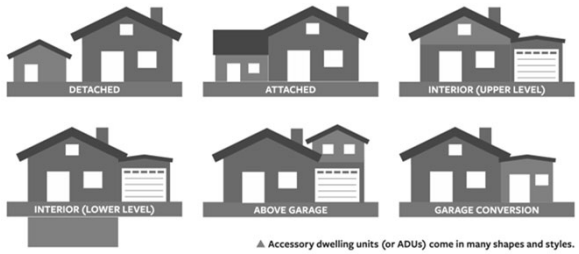
ADU, aka…

- accessory apartment
- backyard bungalow
- basement apartment
- casita
- carriage house
- coach house
- English basement
- garage apartment
- granny flat
- guest cottage
- guest house
- in-law suite
- multi-generational house
- ohana unit
- secondary dwelling unit

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Types of ADUs



▲ Accessory dwelling units (or ADUs) come in many shapes and styles.

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Ownership Issues Related to ADUs

Ownership issues related to ADUs often arise because the ADU is located on the same parcel as the primary home, creating questions about property rights, control, financing, and inheritance.

Common issues include:

- Single Property Ownership
- Co-Ownership and Family Arrangements
- Title and Financing Concerns
- Inheritance and Estate Planning
- Zoning, Land Use and Property Rights Disputes

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Co-Ownership and Family Arrangements

When parents, adult children, other relatives, or a trust help finance or occupy an ADU, disputes can arise over:

- Who owns the ADU structure.
- Rights to occupy the unit.
- Responsibility for maintenance and repairs.
- What happens if the property is sold.

Without a written agreement, these arrangements can become contentious.

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Title and Financing Concerns

Because the ADU is usually part of the same real estate parcel:

- It generally cannot have a separate deed.
- Mortgages and liens typically affect both the main house and the ADU.
- Lenders may require all owners of the property to sign financing documents.

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Inheritance and Estate Planning

If an ADU is intended for a child or elderly parent, problems may arise after the property owner's death:

- The ADU may pass with the entire property under a will or state inheritance laws.
- Occupants of the ADU may not automatically gain ownership rights.
- Heirs may disagree about whether to keep, occupy, rent, or sell the property.

Estate planning can help clarify these issues.

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Zoning, Land Use and Property Rights Disputes

Ownership conflicts can arise when:

- Neighbors challenge ADU construction.
- Property boundaries are unclear.
- Easements or access rights affect the ADU.
- Owners disagree about use restrictions or rental rights.
- Zoning restrictions on and requirements of rental units or owner-occupancy requirements.

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Why Ownership Matters for SSI Benefits

Home Exclusion

- Regardless of its physical form, legally an ADU is part of the same property as the main home. It cannot be bought or sold separately. The owner of the ADU is the owner of the main home.
- To qualify for the home exclusion, an individual must have an ownership interest, legal or equitable, in the home.

You should note however, that without an ownership interest, a home would not count as a resource to the individual, but there are other consequences that flow from not having an ownership interest.

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Why Ownership Matters for SSI Benefits

ISM

- Without an ownership interest, the individual would be required to pay rent or else be charged with in-kind support and maintenance (ISM) in the form of rent-free shelter. Or they could be subject to the value of the one-third reduction (VTR) in their benefits because they are residing in the household of another.

- Paying rent or shelter costs is not a bad thing in and of itself, but if the goal is to maximize benefits, paying rent and expenses or incurring a reduction for ISM is a step in the wrong direction.

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Trust Management

If a trust is paying for the construction of an ADU for the use of the trust beneficiary, the trustee may feel it is necessary, in its fiduciary duty, for the trust to obtain an interest in the ADU.

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Possible Solutions for the Ownership Issue

Equitable Ownership

An "equitable" ownership interest in property can result from personal considerations or from:

- making mortgage payments;
- making or paying for additions to a shelter; or
- making improvements to a shelter.

If an individual alleges an unwritten equitable ownership interest, SSA will gather all the necessary information and forward it to the Regional Chief Counsel for an opinion based on State law.

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Possible Solutions for the Ownership Issue

Condominium or Separate Ownership Structures

- In most jurisdictions, there's a preferred way to create separate ownership of homes: the subdivision process. But what if there's a desire to separate ownership and subdivision isn't an option?
- Some states and local governments allow legal mechanisms, such as condominiumization or lot splits, that can create separate ownership interests for an ADU. However, such situations are currently rare and availability varies significantly by jurisdiction. Local zoning and property laws determine whether separate ownership is allowed.

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Condominiumization

This situation arises most often when:

(1) properties are on top of one another as in multi-story buildings, or

(2) land use regulations make it difficult or impossible to subdivide property horizontally (i.e., minimum lot sizes can't be met; subdivision regulations that preclude a desired site layout; there's no way to provide every lot required street frontage).

Conveniently, all 50 states and the District of Columbia have adopted condominium statutes that allow property to be converted to condominium ownership and back again. Legally, condominiums are 'creatures of the state,' meaning that their existence depends on state laws that lay out the rules for their creation, maintenance, and dissolution.

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Possible Solutions for the Ownership Issue

Partial Life Estate

- One possible avenue that could be explored is the use of a partial life estate. I say "partial" life estate since both the primary house and the ADU are part of the same deed and property, and a regular life estate would give the tenant use of and rights to the entire property. A partial life estate can legally apply to a specific portion or acreage of a larger piece of real estate (such as an ADU) rather than the entire property.
- When you create a partial life estate, you split the legal ownership and use rights for just a designated section of land or a specific structure (such as a house while leaving surrounding acreage out, or vice versa). It can apply to a specific floor, a guest house, or a defined acreage of a larger farm.

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How a Partial Life Estate Works

- The deed or trust must explicitly describe the specific portion assigned to the life tenant. It requires an accurate, legally sound survey and distinct legal description of the specific portion attached to the deed.
- **The Life Tenant**: Obtains the exclusive right to use, occupy, or collect income from that specific part of the property for the rest of their life.
- **The Remainderman**: Holds the future interest to inherit that exact portion of the property automatically when the life tenant passes away, and, if the remainderman is not the original grantor, bypassing probate.
- Duties like taxes and maintenance are typically prorated or assigned based on the terms of the agreement.

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Key Advantages

- Targeted Inheritance**:** Directs a specific house, building, or section of land to a chosen heir, unless it returns to the grantor.
- Probate Avoidance: Transfers the designated portion automatically to the remainderman upon death.
- Continued Control: Guarantees the life tenant a secure place to live or use during their lifetime without interference.

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Critical Risks & Limitations

- Subdivision Restrictions: Local zoning laws, county ordinances, or HOA rules may may legally restrict dividing a single residential structure or lot.
- Shared Control: Depending on whether it is with or without "powers," you may need the remainderman's signature to sell, mortgage, or alter the designated portion later.
- Practical conflicts: Sharing access to utilities, land, or common areas can create friction between the life tenant and the remainderman.
- Maintenance & Taxes: The life tenant remains legally responsible for taxes, insurance, and upkeep on the property, which can get complicated if only a sub-portion is metes-and-bounds defined.
- Medicaid recovery implications: Medicaid estate recovery depends on the rules of the State where the property is located. There may also be transfer implications for the original property owner.

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Tiny Houses

There is some variation in defining a tiny home, but there are examples and they are usually based on floorspace.

- The International Residential Code states that a tiny house's floorspace is no larger than 400 square feet (37 m^2).
- Merriam-Webster says they can be up to 500 ft^2.
- One architectural firm used a threshold of 600 ft^2 to define a tiny home.

What further complicates the definition is that tiny homes may or may not be mobile and lack clearly defined features.

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Tiny Houses

One of the biggest obstacles faced by the tiny-house movement is the difficulty of finding a location in which such a house can be constructed.

- Zoning regulations typically specify minimum square footage for new constructions on a foundation, and
- For tiny houses on wheels, parking on one's own land may be prohibited by local regulations against camping.
- Prohibitions may also extend to mobile homes, RVs, or temporary structures. Many localities do not allow these forms as legal dwellings, primarily due to concerns over stability, sanitation, and permanence.

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Tiny Houses on Wheels

- RV parks do not always allow tiny houses unless they meet the criteria required for Recreational Vehicles (RVs).
- Tiny houses on wheels are considered RVs and are not suitable for permanent residence, according to the Recreational Vehicle Industry Association (RVIA).
- From *RV Business,* "The RVIA will continue to shy away from allowing members who produce products that are referred to as 'tiny houses' or 'tiny homes.'

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SSI Policy on Tiny Houses

- In general, SSA should consider any tiny house built on a foundation with utility hookups as real property, the same as it would consider an ADU or other full-sized house and the same policy considerations would apply.
- Considering a mobile tiny house (which would be considered as personal property), for purposes of the home exclusion, a home can be real or personal property, fixed or mobile, and located on land or water. For purposes of excluding "the land on which the shelter is located," it is not necessary that the individual own the shelter itself.
- EXAMPLE: If an individual lives on their own land in someone else's trailer, the land meets the definition of a home and is excluded. However, if the individual does not own the shelter, it is necessary to consider whether the shelter results in in-kind support and maintenance (ISM) (e.g., rent-free shelter).

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Use of Land

- The use of land alone is not a household cost. Thus, if an individual receives land or the use of land without charge, this does not result in outside ISM. Similarly, third party vendor payments of real property tax, rent or mortgage on land alone do not cause an individual to receive ISM in the form of shelter.
- A trailer space rental fee which is for space alone is not a household operating expense for purposes of determining ISM, However, if the fee is not for use of land alone, that part of the fee which is for water, sewer, etc., is part of the household costs for purposes of determining inside and outside ISM.

EXAMPLE: James Smith, an eligible individual, lives alone in a house trailer they own. The trailer is situated on the property of their sibling, Bill. James pays no rent for the use of the land. Bill provides water and electricity free of charge. The free use of the land results in no ISM to James. However, James is charged with outside ISM based on the CMV of the water and electricity.

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Pooled Trust Management Provisions

- To qualify for exception under the provisions of section 1917(d)(4)(C), a pooled trust must be managed by a non-profit association.
- By law, each trust beneficiary must have a separate account, but the non-profit manager can pool these funds with the funds of other members of this communal trust.
- In some instances, the non-profit manager(s) may employ the services of a for-profit entity to manage some of the financial activities of the trust.

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Pooled Trust Management Provisions

SSA Chief Regional Counsel opinions have identified two distinct categories of cases arising under the pooled trust management provisions.

- The Trust Must be Established and Managed by a Non-Profit Association
- Appointment of Successor Trustees and Co-Trustees

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Policy on Use of For-Profit Entities

If a non-profit association employs the services of a for-profit entity, the non-profit association must maintain ultimate managerial control over the trust. The for-profit entity may handle certain trust functions on behalf of the non-profit association; however, the use of a for-profit entity must always be subordinate to the non-profit managers of a pooled trust under section 1917(d)(4)(C).

For example, the non-profit association must be responsible for:

- determining the amount of the trust corpus to invest;
- removing or replacing the trustee; and
- making the day-to-day decisions regarding the health and well-being of the pooled trust beneficiaries.

NOTE: This list is not intended to be exhaustive. These are a few examples of the type of authority that must vest in the non-profit association. For example, a pooled trust may not meet the criteria in section 1917(d)(4)(C) if the trust includes a provision that allows the for-profit entity to determine whether to make discretionary disbursements from the trust.

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Impermissible Provisions

- The [for profit] Trustee may "pay or apply for the benefit of each Beneficiary such amounts from the principal or income, or both, of the Trust sub-account maintained for such Beneficiary, up to the whole thereof, as the Trustee, in its sole discretion may from time to time deem necessary or advisable
- The [for-profit] Trustee shall have full power and authority in its absolute discretion to do all acts and things necessary to accomplish the purposes of the Trust.
- The Trust Declaration also allows the Trustee to delegate to an agent or agents, any of the fiduciary powers expressed directly or by implication in the Trust.
- The Trust seemed to impermissibly allow the Trust Fund Manager to determine the amount of the Trust corpus to invest. Moreover, the provision allows the Trustee to delegate such powers and duties to the Trust Fund Manager as it sees fit.

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Impermissible Provisions

- The Trustee has the power to delegate to a corporate fiduciary the exercise of any powers, with the same effect as if the Trustee had joined in the exercise of such power."
- The delegation of authority authorized by the Trust appears overly permissive; certain responsibilities cannot be delegated. Assuming that the corporate fiduciary is a for-profit entity, it raises the possibility that the delegation of authority could exceed the limits set forth in POMS SI 01120.225. For example, the delegation provision does not make clear that Secured Futures, as Trustee, must be responsible for determining the amount of the Trust corpus to invest.

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Permissible Provisions

The Trustee may rely on the services of an "Investment Firm," but it now makes clear that the Investment Firm operates under the direction and overall management of the Trustee. The trust has been revised to clearly indicate that the Trustee maintains ultimate managerial control over the Trust.

The trust now provides, for example:

- a list of examples of the types of discretionary payments that may be made "by the Trust Manager or the Trustee under the management of the Trust Manager." It later reiterates that the list is nonexhaustive and that it is meant "to illustrate for the Trustee certain items which the Trustee may, under the management of the Trust Manager, wish to provide for the Beneficiary."
- "Powers of the Trustee" includes express language limiting the Trustee's authority such that it cannot act without the consent of the non-profit Trust Manager, Life Navigators.
- that "all of the foregoing authorities that may be exercised by the Trustee are with the consent of Life Navigators, Inc. pursuant to their managerial duties per 42 U.S.C. § 1396p(d)(4)(C)."

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Appointment of Successor Trustees and Co-Trustees and For-Profit Entities

To qualify for exception under the provisions of section 1917(d)(4)(C), a pooled trust must be managed by a non-profit association. All for-profit entities must be subject to managerial control of the non-profit association including:

Trustee	Managers	Appraisers
Co-trustee	Agents	Accountants
Successor trustee	Investment manager	
Substitute trustee	Care manager	
Replacement trustee	Attorney	
Distribution trustee	Corporate fiduciary	

(Not an all-inclusive list)

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STETSON LAW

Pooled Trusts Intensive

October 21, 2026

There's a New Marshall in Town: Trustee Duties When Trust Payments Go Off Track

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Center for Elder Justice

Access and Justice For All®

There’s a New Marshall in Town: Trustee Duties When Trust Payments Go Off Track

By Megan Brand and Susie Germany, Esq.

Introduction:

Pooled and individual special needs trusts often depend on funding sources governed by court orders, settlement agreements, or statutory obligations. Trustees must not only understand their fiduciary duty to secure these payments but also navigate the legal mechanisms available when payments lapse. This presentation examines the intersection of trust administration and enforcement: identifying funding obligations, pursuing delinquent payments, identifying when to engage counsel and then coordinating with them and documenting compliance. We will also discuss scalable tracking systems that help trustees manage recurring payments across multiple beneficiaries and avoid gaps that could jeopardize benefits or trust viability.

Types of Payments that may be assigned to a trust:

There are a number of different types of payments that may be assigned to a trust. As a trust administrator, the most common we see are:

a. Annuities (such as Structured Settlements for Personal Injury)
b. Military Survivor Benefit Plan (SBP)
c. A stand-alone contract or agreement through a court settlement
d. Child or Spousal Support
e. A judgement or lien
    i. Erroneous filings in court to consider trust a conservatorship asset. Judge assesses attorney fees to the petitioning party.
    ii. Trustee must petition the court to protect an asset such as a home and pays for the attorney fees (due to limited resources) and then records a lien against the property for payment when it is sold.
f. A will that is directed to pay into a 3rd party trust
g. Conserved Assets that are court ordered to fund a trust

What can and cannot be assigned to trust

The Social Security Program Operations Manual System[1] (POMS) gives us great direction about what can and cannot be assigned to trust. Specifically, POMS SI0120.200 G.1.c. states the following cannot be assigned to trust:

h. Temporary Assistance to Needy Families (TANF)/Aid to Families with Dependent Children (AFDC);
i. Railroad Retirement Board-administered pensions;
j. Veterans' pensions and assistance;

[1] https://secure.ssa.gov/apps10/poms.nsf/Home?readform

k. Federal employee retirement payments (CSRS, FERS) administered by the Office of Personnel Management;
l. Social Security Title II and SSI payments;
m. Private pensions under the Employee Retirement Income Security Act (ERISA) 29 U.S.C.A. § 1056(d)).

How to Properly structure the payments to trust:

POMS SI0120.200 G.1.d.[2] addresses the Assignment of Income and Irrevocable assignment through court order. It states as follows: "A legally assignable payment that is assigned to a trust or trustee is income for SSI purposes, to the individual entitled or eligible to receive the payment, **unless** an SSI income exclusion applies or the assignment is irrevocable. We consider assignment of payment by court orders to be irrevocable. For example, child support or alimony payments paid directly to a trust or trustee because of a court order are considered irrevocably assigned and thus not income. Also, U.S. Military Survivor Benefit Plan (SBP) payments assigned to a special needs trust are not income because the assignment of an SPB annuity is irrevocable. For more information on SPB annuities, see SI 01120.201J.1.e."

A Properly drafted Will should include language such as "I give all my remaining estate to my son, John Doe, if he survives me, to be held in trust subject to the provisions of Article 3 of The John Doe Supplemental Needs Trust".

For Court Orders and Settlement Documents it is important to direct payments to Trust rather than the Beneficiary –"Pay to the Order of John Doe" vs. "Pay to the Order of the John Doe Special Needs Trust". Similarly for Beneficiary Designations, name the Trust rather than the Beneficiary (Example: Beneficiary—Jane Doe vs. The Jane Doe Special Needs Trust).

As discussed above, Annuities, Structured Settlements, and other Periodic Payments – if the assignment is revocable, the payment can be counted as income to the beneficiary. The attorney should identify the source of every anticipated trust payment before deciding how the payment should be structured.

"Payable to the Trust" is preferable to "Payable to the Beneficiary then deposited into the Trust"

All the ways in which this can go off track:

[2] https://secure.ssa.gov/apps10/poms.nsf/Home?readform

As a trust administrator and attorney who represents them and other fiduciaries, the authors have seen many ways in which payments assigned to trust can go off track. Please consider the following examples by way of case scenario.

- Beneficiary and/or their representative calls or writes the annuity company and redirects the payment to them personally instead of the trust.
  Tyler: is entitled to annuity benefit for a PI Settlement in which he was injured as a minor. Payments were irrevocably assigned to the pooled trust FBO Tyler. Fast forward to the point in time in which Tyler is an adult. He is not happy with his pooled trust administrator because they have denied some of his requests for Medical Marijuana and other expenses because they were not preapproved or properly documented. Tyler calls the annuity company and directs the next annuity payment to himself. The annuity company complies.

- The individual or entity directed to pay the trust files for bankruptcy. The individual or entity directed to pay the trust simply stops paying.
  Eleanor: Eleanor is injured significantly in an accident and sustains a brain injury and her fiancé is killed. In addition to the meager insurance payout, her attorney negotiates a separate settlement in which the driver and his parents are ordered to pay one monthly payment to the pooled trust. The court orders this arrangement. Eleanor spends her trust down nearly every month to meet her needs. Case manager notices her balance is dwindling quickly and realizes the monthly deposits have ceased. Trustee discusses with Eleanor. Eleanor is hesitant to agree to trustee bringing in counsel due to cost. Trustee ultimately determines they have an obligation to pursue this payment. In the meantime, counsel for trustee learns that the son is filing for bankruptcy, his parents are divorcing and his father is also contemplating bankruptcy.

- Successor trustee to initial trust ordered to pay does not see the order in their file review
  Jack: Jack and his attorney worked out an arrangement in which a family trust paid out a lump sum for funds due to him to the 3rd party pooled trust and then made ongoing monthly payments to the 3rd party pooled trust. The family trust was quite substantial. This was all codified in a court order. Fast forward a few years and the pooled trust trustee receives an agreement to release and indemnify the trustee of the family trust. It turns out that when the bank trustee changed from one financial institution to the other, the monthly deposits did not continue.

- Personal Representative of Estate steals the money intended for the trust or there is gross negligence

  Sally and John, both born with intellectual developmental disabilities, are the beneficiaries of their father's estate, along with their sister Cheryl. When their father Dan died, he named his lifelong friend and attorney, Bob, as Personal Representative of his estate. Years before Dan's death, Bob had drafted Dan's will, and created a testamentary special needs trust for Sally and John. The will left the estate in equal shares for each of Dan's children, but contained a confusing clause to equalize the estate if the assets in his estate were not liquid at the time of his death. After Dan's death, Bob sold Dan's house, liquidated his assets, and made a large distribution to Cheryl to help fund a new business she was starting. Three years went by, and Bob never funded the special needs trusts for Sally and John. The named trustee of Sally and John's trust opens a trust action with the court to seek an accounting, inventory for the estate and request the funding of the trust. Bob, an attorney, hires counsel who then begins litigation fighting the trustee of the SNT. After years of costly litigation and not having their Trusts funded, the stress and frustration of the litigation has exhausted what little assets the Beneficiaries do have and it becomes evident that the Estate no longer has the assets to fully fund the Trusts. The Personal Representative proposes a settlement wherein they would fund the Trusts with the remaining Estate funds, in exchange for a full release of liability.

- Court orders the attorney and/or party to pay an obligation, but the trustee must reduce it to a judgement or lien

  Olivia: Olivia, a teenager, has a significant developmental disability due to an injury at birth. Due to numerous circumstances, the Professional Guardian decides to move Olivia out of the trust-owned home to a host home (Dad had been paid, live-in caregiver). Trustee makes the decision to sell the home. In a last-ditch effort for control, dad (through his attorney) files for a new guardian and a conservator. Only assets listed on the petition for conservator are the trust and the trust-owned home. Judge puts dad and his attorney on notice that if they proceed with the petition for conservator (since there are no assets to be overseen by the conservatorship) that the judge will entertain a motion for attorney fees for trustee and guardian.
  Dad and his attorney proceed and all motions were denied.
  Counsel for guardian petitions the court for attorney fees to respond to this erroneous petition and court grants it. Nearly $40,000 in attorney fees is assessed jointly and severally to the dad and his attorney **and payable to the trust**. Dad files

for bankruptcy. Attorney for dad begins all kinds of frivolous arguments, including that he was not served timely (he was).

- One of the assets of the estate is to be paid to the trust and the PR believes it is their asset
  Paul: Paul's father dies very suddenly in a terrible auto accident. Nearly all of the funds from his father's estate are payable to the 3rd Party SNT for the benefit of Paul. The main exception is "personal property" belonging to Paul's father. Paul's father's wife (not Paul's mother) is the PR of the estate. She determines a boat is "personal property" and transfers it to herself. Paul's mother (also guardian) believes the boat should go into the residuary of the trust, of which Paul's SNT is the beneficiary.
  In the course of settling the "boat debacle", it came to light that there were multiple questionable transactions related to the estate administration by the PR.

  The scenarios described above are drawn from the authors' real-world experiences. However, they represent only a few of the many circumstances in which assets intended for a trust may never reach it. For example, a conservator may fail to fund a trust as ordered, whether partially or entirely, or a will may designate a trustee who is never informed of the appointment. In situations such as these, trustees often have little or no way of knowing that assets or interests exist for which they are responsible.

Obligations of trustee and their counsel

What is the duty of a successor trustee or conservator to locate, secure assets? How far do they have to go? The scope of any court order may define that duty. Other times it may be according to state trust law or the uniform trust code.

Under the **Uniform Trust Code (UTC)**, a trustee's obligation to locate, marshal, and secure trust assets stems from several overlapping fiduciary duties outlined in **Article 8 (Duties and Powers of Trustee)**.

The primary statutory requirements and relevant citations for locating and securing assets include:

1. **The Duty to Collect Trust Property (UTC § 812)**

   This is the foundational section requiring a trustee to actively gather the trust's assets.

   - **The Rule:** A trustee must take "reasonable steps" to compel a former trustee or any other person to deliver the trust property to the trustee.

- **Application:** This mandates that the trustee search for, identify, and take physical or legal custody of all properties belonging to the trust at the inception of their administration.

2. The Duty to Control and Protect Trust Property (UTC § 809)

Once assets are located, the trustee has an immediate duty to secure them.

- **The Rule:** "A trustee shall take reasonable steps to take control of and protect the trust property."
- **Application:** "Securing" assets under this rule includes taking physical possession of tangible items, changing locks on real estate, moving funds to secure trust bank accounts, and purchasing adequate insurance to protect against loss or damage (**UTC § 816)**

3. Recordkeeping and Earmarking (UTC § 810)

Locating and securing assets requires proper legal separation and identification to prevent asset diversion.

- **The Rule:** A trustee must keep adequate records of the administration of the trust (**UTC § 810(1)**) and must keep trust property separate from the trustee's own property (**UTC § 810(2)**)
- **Application:** The trustee must ensure that titled assets (like bank accounts, real estate, and stocks) are properly re-titled in the name of the trust rather than held individually, a process known as "earmarking".

4. General Duty of Prudent Administration (UTC § 804)

The process of locating and securing assets must be executed competently.

- **The Rule:** A trustee must administer the trust as a prudent person would, exercising reasonable care, skill, and caution.
- **Application:** If a trustee fails to thoroughly search for missing assets or allows assets to waste away due to lack of security, they may be found in breach of this standard.

5. Accompanying Power to Collect Property (UTC § 816(1)(a))

To enable the trustee to fulfill these duties, the UTC grants the explicit statutory authority to do so.

- **The Rule:** A trustee has the specific power to "collect trust property and accept or reject additions to the trust property".

- **Application:** The trustee has the authority and responsibility to evaluate whether an addition should be accepted.

  Just because an asset **can** be assigned to the trust, does not mean it **should** be assigned to the trust.

Furthermore, we need to explore What Happens if a Trustee Fails to Locate and Secure All Assets. Beneficiaries can file a civil lawsuit for **breach of fiduciary duty** and **negligence** against a trustee who fails to locate and secure trust assets.

When a trustee takes over a trust, they have a legal duty to identify, collect, and safeguard all trust property. Failing to do so harms the beneficiaries and exposes the trustee to legal claims.

Core Causes of Action:

- **Breach of Fiduciary Duty:** Trustees must manage trust property with the care, skill, and caution of a prudent person. Leaving assets uncollected, uninspected, or unsecured (such as leaving real estate abandoned or failing to track down missing financial accounts) violates this standard of care.
- **Breach of the Duty to Collect and Protect Assets:** A trustee has an affirmative obligation to take control of trust property promptly. If they fail to secure tangible property, financial accounts, or real estate—leading to loss, theft, or damage—they can be sued for the resulting economic harm.
- **Common Law Negligence:** If the trustee acts carelessly or fails to perform basic investigative steps to find assets that reasonably belonged to the trust, beneficiaries can claim ordinary or professional negligence.

Available Remedies and Court Actions:

If a trustee fails to secure assets, beneficiaries can petition the probate court for specific legal remedies:

- **Surcharge (Financial Damages):** The court can order the trustee to pay out of their own personal pocket to replace the value of any lost, uncollected, or mismanaged assets, plus lost interest or earnings.
- **Removal or Suspension:** Beneficiaries can ask the court to remove the negligent trustee and appoint a professional or successor trustee.
- **Compelling an Accounting and Inventory:** The court can order the trustee to produce a full forensic accounting of all assets they have managed or failed to locate.
- **Attorney's Fees:** Courts may order the negligent trustee to pay the beneficiaries' legal fees if their failure to act forced a court battle.

Finally, the obligation to pay funds to a trust, or the assignment of funds for the trust's benefit, constitutes a trust asset. Trustees have a fiduciary responsibility to account for,

monitor, and pursue the collection of all assets and income due to the trust. Attorneys representing trustees should advise their clients of these obligations and the potential consequences of failing to protect or recover trust assets, including possible liability for breach of fiduciary duty.

Practical Advice for Trust Administration

Trustees have a fiduciary duty to identify, monitor, and collect assets owed to the trust. A well-organized intake process is the first step in ensuring that all known assets and future payment obligations are identified and documented.

Once identified, payments due to the trust should be recorded in a reliable tracking system that captures the source, amount, due date, and payment status of each obligation. Regular reviews of expected payments help trustees quickly identify missed or delayed payments.

Assets owed to the trust should be accounted for through the trust's accounting records or a separate receivables tracking system. Maintaining accurate records demonstrates that the trustee is actively monitoring trust property.

When a payment is missed, trustees should promptly investigate and follow up with the payor. If the obligation is disputed, significant, or remains unpaid despite collection efforts, legal counsel should be consulted. Trustees should also consider whether statutory interest or other remedies may be available.

In deciding whether to pursue collection, trustees must balance the anticipated costs of recovery against the value of the asset while remaining mindful of their fiduciary duty to protect trust property. This is not a “one size fits all” model –Trustees should consider what response is *reasonable under the circumstances*. Consider factors such as the value of the trust, the likelihood of successful recovery, the strength of the trust’s legal claim, the identity and solvency of the person or entity holding the asset, the potential impact on the beneficiary, and if failure to act could constitute a breach of fiduciary duty. This is not necessarily a mathematical formula – rather, it is a documented decision-making process. The Trustee must identify the asset, consider the circumstances, and make an informed fiduciary decision.

An effective attorney relationship can be invaluable in these situations. Trustees benefit from working with attorneys who understand trust administration, can clearly evaluate the facts, establish a timeline of events, and assess both known assets and newly discovered obligations. A well-prepared inventory of relevant documents and information allows counsel to provide efficient and practical guidance.

Ultimately, effective trust administration requires more than identifying assets. The trustee needs to close the loop. The process should look something like this:

- Identify the asset →
- establish the trust's entitlement →
- determine where the asset/payment is →
- secure it →
- monitor it →
- reconcile it →
- investigate discrepancies →
- pursue appropriate remedies →
- document the resolution.

That process should continue throughout the administration. **The strongest administration is not the one in which nothing ever goes wrong.** It is the one in which, when something does go wrong, the trustee can show:

- We identified it.
- We investigated it.
- We evaluated the options.
- We took reasonable action.
- And we documented why.

THERE'S A NEW MARSHALL IN TOWN

Trustee Duties When Trust Payments Go Off Track

By Megan Brand and Susie Germany, Esq.

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- WANTED: For 20 years of operating an independent law practice, Fiduciary Wrangler, Former Deputy Public Administrator.
- SPECIAL SKILLS: Can advise a professional fiduciary, operate a tractor, and teach Megan how to load for bear — possibly before lunch.
- FAMILY OUTFIT: Three grown children, including two active-duty service members.
- CAUTION: May be armed with decades of legal experience and unusually practical wilderness knowledge as a true Colorado cowgirl



- WANTED: Executive Director of CFPD, for the ongoing wrangling of pooled and individual trusts across the Colorado frontier.
- PLACE OF ORIGIN: Kansas-raised, with just enough cowgirl in her blood to make poor decisions seem well-managed.
- KNOWN TO TRAVEL IN LARGE NUMBERS: Raising a herd of six kids at home, proving that managing a nonprofit may actually be the quieter part of her day.
- CAUTION: Approaches complicated trust matters with calm authority and may spontaneously organize the entire posse.

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2

Ridin' the Trail: What We'll Cover

Payments Assigned to Trust
What can (and can't) be directed to a trust, and how to structure it right

When Payments Go Off Track
Six real-world case scenarios where funding derailed

Trustee & Counsel Obligations
Trustee duties to locate, collect, and protect trust assets

Practical Administration
Tracking systems and a step-by-step process for closing the loop

2

3

Keeping Watch Over the Trust

Pooled and individual special needs trusts often depend on funding from court orders, settlement agreements, or statutory obligations. Trustees must understand their fiduciary duty to secure these payments and navigate the legal mechanisms available when payments lapse.

This session covers:

- Identifying funding obligations
- Pursuing delinquent payments
- Knowing when to engage counsel and coordinating with them
- Documenting compliance
- Scalable tracking systems for recurring payments across beneficiaries

3

4

Types of Payments Assigned to Trust

Part 1 of 2 — the most common sources trust administrators see:

Annuities

Such as structured settlements for personal injury

Military Survivor Benefit Plan (SBP)

Assigned annuity payments to a special needs trust

Court Settlement Contract

A stand-alone contract or agreement through settlement

Child or Spousal Support

Court-ordered support payments directed to trust

4

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Types of Payments Assigned to Trust

Part 2 of 2:

Judgment or Lien

- Erroneous filings that treat the trust as a conservatorship asset. The judge assesses attorney fees to the petitioning party
- Trustee may need to petition the court to protect an asset (like a home), pay attorney fees, and record a lien for payment when it sells

Will Directing Payment

A will directed to pay into a 3rd-party trust

Conserved Assets

Court-ordered to fund a trust

5

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Off Limits: What Cannot Be Assigned

POMS SI 0120.200 G.1.c. names these as ineligible for assignment to trust:

- TANF / AFDC (Temporary Assistance to Needy Families)
- Railroad Retirement Board–administered pensions
- Veterans' pensions and assistance
- Federal employee retirement (CSRS, FERS) via OPM
- Social Security Title II and SSI payments
- Private ERISA pensions (29 U.S.C.A. § 1056(d))

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How to Properly Structure Payments

POMS SI 0120.200 G.1.d. — Assignment of Income

A legally assignable payment assigned to a trust is income for SSI purposes, unless an exclusion applies or the assignment is irrevocable. Court-ordered assignments (child support, alimony, Military SBP) are considered irrevocable and thus not income.

Two Golden Rules for Drafting

A Properly Drafted Will

"I give all my remaining estate to my son, John Doe, if he survives me, to be held in trust subject to the provisions of Article 3 of The John Doe Supplemental Needs Trust."

Identify the Source First

Attorneys should identify the source of each anticipated trust payment before deciding how to structure it. Revocable assignments can count as income.

7

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Draft It Right: Payable to the Trust

	INCORRECT	CORRECT
Court Orders & Settlements	*"Pay to the Order of John Doe"*	*"Pay to the Order of the John Doe Special Needs Trust"*
Beneficiary Designations	*Beneficiary — Jane Doe*	*Beneficiary — The Jane Doe Special Needs Trust*
Payment Structure	*Payable to the Beneficiary, then deposited into the Trust*	*Payable directly to the Trust*

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Wanted: When Payments Go Off Track

Six real cases where trust funding derailed

9

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WANTED: FUNDING GONE ASTRAY

Case 1: Tyler

The redirected annuity payment

Tyler is entitled to annuity benefits from a personal injury settlement, irrevocably assigned to his pooled trust. As an adult, unhappy that the trustee denied requests for medical marijuana and other undocumented expenses, Tyler calls the annuity company himself and redirects the next payment to himself. The annuity company complies.

WHAT DO YOU RECKON?

What is your obligation for recovering this payment?
What about future payments?
When do you bring in an attorney?
What do you do when a sternly written letter from your attorney goes unnoticed?

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WANTED: FUNDING GONE ASTRAY

Case 2: Eleanor

The payments that quietly stopped

Eleanor sustains a brain injury in an accident that kills her fiancé. Beyond a modest insurance payout, her attorney negotiates a court-ordered (civil settlement) monthly payment from the driver and his parents to her pooled trust. Eleanor draws down the trust each month to meet her needs. Her case manager notices the balance dwindling and discovers the deposits have ceased. Eleanor hesitates to bring in counsel because of the cost, but the trustee determines they have an obligation to pursue it. Counsel then learns the son is filing for bankruptcy, and his parents are divorcing, with the father also contemplating bankruptcy.

WHAT DO YOU RECKON?

How does the bankruptcy complicate this case?
How do you balance your fiduciary duty to Eleanor and weigh that with her getting nothing at all?
At what point do you get the court involved?

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WANTED: FUNDING GONE ASTRAY

Case 3: Jack

Lost in the trustee handoff

Jack's attorney arranged for a substantial family trust to pay a lump sum, plus ongoing monthly payments, to his third-party pooled trust, all codified in a court order. Years later, the pooled trust trustee receives an agreement to release and indemnify the family trust's trustee. It turns out that when the family trust's corporate trustee changed institutions, the monthly deposits simply never continued.

WHAT DO YOU RECKON?

Does the release to indemnify include the necessary provisions for you to sign as trustee? What about statutory interest?
What liability, if any, did the pooled trust have in not recognizing these deposits had not been made?

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WANTED: FUNDING GONE ASTRAY

Case 4: Sally and John

The estate that was never funded

Sally and John, both born with intellectual developmental disabilities, are beneficiaries of their father Dan's estate alongside their sister Cheryl. Dan's lifelong friend and attorney Bob serves as Personal Representative. Bob sells the house, liquidates assets, and makes a large distribution to Cheryl for her new business. Three years pass; the trusts for Sally and John are never funded. The named trustee opens a court action to compel funding. Years of costly litigation exhaust what little the beneficiaries have, and the estate no longer has assets to fully fund the trusts.

WHAT DO YOU RECKON?

Are you, the name trustee, tracking all deposits that are made payable to the trust as part of the estate?
At what point do you bring in counsel to review accountings and court filings?
When do you need to bring in an attorney or GAL to represent the beneficiaries?

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WANTED: FUNDING GONE ASTRAY

Case 5: Olivia

The frivolous petition

Olivia, a teenager with a significant developmental disability from a birth injury, is moved by her Professional Guardian from a trust-owned home to a host home. The trustee decides to sell the home. In a last-ditch bid for control, her father petitions for a new guardian and conservator, listing only the trust and the trust-owned home as assets. The dad proceeds despite the judge's warning; the court denies the motions. The court assesses nearly $40,000 in attorney fees jointly against Dad and his attorney, payable to the trust. Dad files for bankruptcy.

WHAT DO YOU RECKON?

An award of attorney fees can feel like a win, until you realize that you, as trustee, now have the obligation to track them down?
How do you assess the cost of additional attorney fees to track down what is owed against your fiduciary duty?

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WANTED: FUNDING GONE ASTRAY

Case 6: Paul

The boat debacle

Paul's father dies suddenly in an auto accident. Nearly all the estate funds are payable to Paul's third-party SNT with one exception: "personal property" belonging to his father. The Personal Representative, his father's wife (not Paul's mother), determines an extravagant boat qualifies as personal property and transfers it to herself. Paul's mother, also his guardian, believes the boat should fall into the trust's residuary. Settling the "boat debacle" brings multiple questionable transactions by the PR to light.

WHAT DO YOU RECKON?

Is it our duty as trustee to participate in mediation to settle a dispute?
How do you consider the remainder beneficiaries or benefit programs when such an asset may be seen as a transfer without fair consideration?
Have you considered utilizing a special administrator for forensic accounting, etc?

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Common Threads Across the Cases

These aren't outliers; they're patterns. Assets intended for a trust may never reach it when:

Beneficiaries self-redirect
A payor complies with a call from the beneficiary, bypassing the trust

Payors default or vanish
Bankruptcy, divorce, or institutional change interrupts payments silently

Records don't transfer
Successor trustees never see the order; institutional handoffs drop the ball

Fiduciaries breach duty
A PR delays, mismanages, or diverts funds meant for the trust

Litigation exhausts assets
Court battles to compel funding can consume the very assets at stake

Ambiguity gets exploited
Vague terms like "personal property" invite self-serving interpretation

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The Law of the Land

Trustee & counsel obligations under the Uniform Trust Code

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Trail Note

36 states follow the Uniform Trust Code, and several states rely on their own comprehensive or independent trust statutes instead:



- California
- Delaware
- Georgia
- Indiana
- Iowa
- Louisiana
- Nevada
- New York
- Oklahoma
- South Dakota
- Texas
- Washington



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UTC § 812

Duty to Collect Trust Property

THE RULE

A trustee must take "reasonable steps" to compel a former trustee or any other person to deliver trust property to the trustee.

APPLICATION

This mandates that the trustee search for, identify, and take physical or legal custody of all property belonging to the trust at the inception of their administration.

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UTC § 809

Duty to Control and Protect Trust Property

THE RULE

"A trustee shall take reasonable steps to take control of and protect the trust property."

APPLICATION

Securing assets includes taking physical possession of tangible items, changing locks on real estate, moving funds to secure trust bank accounts, and purchasing adequate insurance against loss or damage (UTC § 816).

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UTC § 810

Recordkeeping and Earmarking

THE RULE

A trustee must keep adequate records of trust administration (§ 810(1)) and keep trust property separate from the trustee's own property (§ 810(2)).

APPLICATION

Titled assets like bank accounts, real estate, and stocks must be properly retitled in the trust's name rather than held individually, a process known as "earmarking."

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UTC § 804

General Duty of Prudent Administration

THE RULE

A trustee must administer the trust as a prudent person would, exercising reasonable care, skill, and caution.

APPLICATION

If a trustee fails to thoroughly search for missing assets, or allows assets to waste away for lack of security, they may be found in breach of this standard.

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UTC § 816(1)(a)

Accompanying Power to Collect Property

THE RULE

A trustee has the specific power to "collect trust property and accept or reject additions to the trust property."

APPLICATION

The trustee has both the authority and responsibility to evaluate whether to accept an addition. Just because an asset CAN be assigned to the trust does not mean it SHOULD be.

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Just Because You Can...

...doesn't mean you should.

An asset CAN be assigned to the trust under UTC § 816(1)(a), but the trustee has both the authority and the responsibility to evaluate whether that addition should actually be accepted.

Every acceptance decision should weigh the trust's purpose, benefits eligibility, encumbrances, and administrative burden, not just legal eligibility.

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If a Trustee Fails to Locate & Secure Assets

Beneficiaries can bring a civil lawsuit. Core causes of action:

Breach of Fiduciary Duty

Leaving assets uncollected, uninspected, or unsecured (abandoned real estate, untracked accounts) violates the standard of care.

Breach of Duty to Collect & Protect

Failing to promptly secure tangible property, financial accounts, or real estate, leading to loss, theft, or damage.

Common Law Negligence

Acting carelessly or failing basic investigative steps to find assets that reasonably belonged to the trust.

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Remedies & Court Actions Available

Surcharge

Court orders the trustee to personally pay for lost, uncollected, or mismanaged assets, plus lost interest or earnings.

Removal or Suspension

Beneficiaries can ask the court to remove the negligent trustee and appoint a professional or successor trustee.

Compel Accounting & Inventory

The court can order a full forensic accounting of all assets managed, or failed to locate.

Attorney's Fees

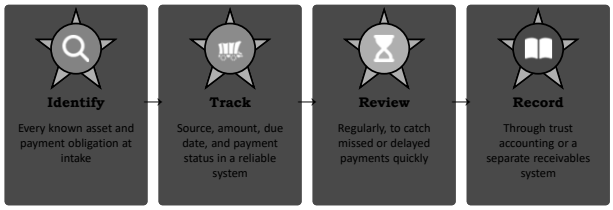
Courts may order the negligent trustee to pay beneficiaries' legal fees if their failure forced a court battle.

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Build a System, Not a Scramble

A well-organized intake process is the first step to ensuring all known assets and future obligations are identified and documented.



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Deciding Whether to Pursue Collection

Not a "one size fits all" model — weigh cost of recovery against the asset's value. Consider:

- Value of the trust
- Likelihood of successful recovery
- Strength of the trust's legal claim
- Identity and solvency of the person or entity holding the asset
- Potential impact on the beneficiary
- Whether failure to act could breach fiduciary duty

Not a mathematical formula, but a documented decision-making process. Identify the asset, consider the circumstances, and make an informed fiduciary decision.

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Closing the Loop

Effective administration needs more than identifying assets. The trustee must close the loop:

1. Identify the asset (Assignment of income)
2. Secure it
3. Monitor it
4. Reconcile it
5. Investigate discrepancies
6. Pursue remedies and document the resolution!

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The Strongest Administration

isn't the one in which nothing ever goes wrong.

It's the one where, when something does go wrong, the trustee can show:

- ✓ We identified it.
- ✓ We investigated it.
- ✓ We evaluated the options.
- ✓ We took reasonable action.
- ✓ And we documented why.

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Questions, Pardner?



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STETSON LAW

Pooled Trusts Intensive

October 21, 2026

Legislative Update/Call to Action

STETSON LAW

Center for Elder Justice

Access and Justice For All®

Stetson 2026 National Conference
Legislative Update Outline
Roxanne Chang, David Goldfarb, Kerry Tedford-Coles

1. OBBBA: Where Are We Now?

Interim Final Rule on Community Engagement Requirements for Medicaid Expansion

1.1 Medicaid Expansion: The Basics

- Optional program covering adults with incomes below 138% of the Federal Poverty Level (approximately $22,025 per year for a single individual).
- Not to be confused with categorical eligibility under SSI or an HCBS waiver program.

1.2 OBBBA Work Requirements: Overview

States must implement work reporting requirements by January 1, 2027.

Individuals must show either:

- 80 hours per month of work, volunteering, or half-time study; **or**
- Earnings of at least the federal minimum wage × 80 hours (approximately $580 per month).

1.3 Categorical Exemptions: Overview

- "Medically frail" individuals.
- Parents, guardians, caretaker relatives, or family caregivers of:
    - A dependent child (under 14); or
    - A disabled individual.
- Pregnant and postpartum individuals, and more.

1.4 Defining the Caregiver Exemptions

- **Parent:** Legal mother or father, including by adoption under state law.
- **Guardian:** Court-appointed adult caregiver and decision-maker.

- **Caretaker Relative:** Relative by blood, adoption, or marriage who lives with and is primarily responsible for the individual's care. States may expand the defined relationships.
- **Family Caregiver:** Adult providing regular, non-incidental assistance, qualifying under any of three scenarios:
    - Resident;
    - Nonresident relative; or
    - Non-relative providing 80+ hours per month.

1.5 Key Terms Underlying the Caregiver Definitions

- **Dependent Child:** Age 13 or under and relies on another for care.
- **Disabled Individual:** Meets the ADA definition (28 C.F.R. § 35.108); any age; need not be Medicaid eligible on a disability basis.

1.6 Medical Frailty Exemption: Full Definition

Condition must "significantly impair" the ability to comply with the community engagement requirement, where the individual is:

- Blind or disabled (per SSA § 1614);
- Living with a substance use disorder (excludes "stable recovery," defined by CMS as 5+ years in recovery);
- Living with a disabling mental disorder;
- Living with a physical, intellectual, or developmental disability that significantly impairs one or more activities of daily living; or
- Living with a serious or complex medical condition (broadly defined: life-threatening, seriously disabling, high pain or interruption to life activities, heavy caregiver burden, frequent monitoring, multi-organ, multi-specialty, high-risk treatment, etc.).

1.7 Short-Term Hardship Exceptions

- Hospitalization or institutionalization.
- Travel for medical care (self or dependent).
- Federal emergency or disaster declarations.
- High local unemployment.

1.8 Litigation Controversies

Narrowing issue: States must verify not just a qualifying condition, but that it "significantly impairs" the ability to work.

Case: Massachusetts v. Oz (D. Mass.)

- Brought by 26 states and D.C. against CMS Administrator Mehmet Oz, CMS, HHS Secretary Robert F. Kennedy Jr., and HHS, challenging the Interim Final Rule.
- On July 30, 2026, Judge Richard Stearns denied a preliminary injunction, finding no irreparable harm (CMS covers 90% of state implementation costs).
- The merits of the claims were not decided; the case continues.

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2. New Provider Tax Limits

2.1 What Are Provider Taxes?

Medicaid provider taxes are mandatory fees, assessments, or charges that state governments place on health care providers (such as hospitals, nursing homes, and managed care organizations) to help finance the state's required non-federal share of Medicaid spending.

2.2 CMS Actions After OBBBA

Final Rule: Generally Redistributive Requirement

- Implements H.R. 1 by barring provider taxes structured to disproportionately burden Medicaid.

Proposed Rule CMS-2452-P

- Released July 21, 2026.
- The proposed rule would implement H.R. 1's new provider tax limits and beyond.
- CMS estimates the rule would reduce federal Medicaid expenditures by $246 billion over 10 years compared to the Congressional Budget Office's original estimate of $183 billion in deficit reduction from the OBBBA's provider tax provisions.

2.3 Budget Neutrality for Section 1115 Waivers

Section 1115 waivers let states test Medicaid programs that go beyond standard federal rules, but they must be "budget neutral," meaning they cannot cost the federal government more than Medicaid would have without the waiver.

A June 11 letter from CMS, implementing H.R. 1, makes that test much tougher starting January 1, 2027.

States will now:

- Need the CMS Chief Actuary to certify budget neutrality before approval;
- Need to count administrative and indirect costs for the first time; and
- Lose the flexibility that previously let them cover people or services not otherwise allowed under Medicaid.

A forthcoming rule is also expected to cap waivers at five years.

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3. End of Temporary Status for Haiti and Other Countries

3.1 Impact on the Health Care Workforce

- Impacts when there is already a shortage of workers.
- Immigrants represent 28% of direct care workers nationwide.

Source: PHI Midterm Policy Brief Series: *Support Immigrants*
https://www.phinational.org/resource/phi-midterm-policy-brief-series-support-immigrants/

3.2 South Florida Health Care Industry

https://www.nbcmiami.com/news/local/revoking-tps-for-haitians-would-create-crisis-for-south-florida-health-care-industry/3758754/

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4. Community Integration

4.1 Background on Olmstead v. L.C. (1999)

The Supreme Court held that the unjustified segregation of people with disabilities in institutions is a form of discrimination under Title II of the Americans with Disabilities Act.

The Court ruled that states must provide community-based services when:

- Treatment professionals find it appropriate;
- The individual does not oppose it; and
- The placement can be reasonably accommodated given the state's resources and the needs of others with disabilities.

Olmstead remains the legal foundation for the shift toward home and community-based services, including many Medicaid waiver programs that special needs clients rely on today.

4.2 Department of Justice Memo

On June 18, 2026, the Justice Department's Office of Legal Counsel issued a memorandum reinterpreting federal disability rights obligations under the ADA and Section 504 as they relate to *Olmstead*.

The memo concludes that neither the ADA nor Section 504 requires states to provide services to people with disabilities in the most integrated setting appropriate to their needs, and it suggests that DOJ lacked authority to adopt an "integration mandate" in its Title II regulations.

In a July 2026 Federal Register notice, the Department stated that it plans to revisit its *Olmstead* guidance in light of the Supreme Court's *Loper Bright* decision and will not rely on that guidance when enforcing Title II of the ADA.

The memo:

- Does not change the law;
- Does not overturn the *Olmstead* decision;
- Does not invalidate existing court orders; and
- Does not prevent individuals from bringing *Olmstead* claims.

However, because OLC opinions apply to all executive branch agencies, the interpretation is likely to affect how DOJ and HHS approach enforcement, including existing *Olmstead* settlements and agreements.

4.3 The Arc / DOJ Olmstead Enforcement Resources

DOJ Olmstead Enforcement: Disability Rights Resources | The Arc

https://www.phinational.org/resource/phi-midterm-policy-brief-series-support-immigrants/

4.4 Texas v. Kennedy

On September 23, 2026, the U.S. District Court for the Northern District of Texas entered an order implementing a settlement between the federal government, Texas, and four other states that had challenged HHS's 2024 Section 504 regulations.

The order vacates the provisions of those regulations referencing community integration for people with disabilities.

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5. Fraud, Waste, and Abuse Initiatives

5.1 New Scrutiny on So Many Fronts

5.2 Impact on Social Security Overpayments

An OIG audit determined 46% of the overpayment notices it reviewed did not meet SSA's policy requirements.

Deficiencies included:

- Missing explanations of how and when the overpayment occurred;
- Omitted reconsideration and waiver rights;
- Inaccurate dollar amounts;
- Conflicting or unclear language; and
- Insufficient detail on calculation methods.

Source: *Audit Identifies Issues in SSA's Overpayment Notices, Impacting Beneficiaries' Understanding and Program Integrity | SSA Office of the Inspector General*

https://oig.ssa.gov/news-releases/2026-09-04-audit-identifies-issues-in-ssa%E2%80%99s-overpayment-notices-impacting-beneficiaries%E2%80%99-understanding-and-program-integrity/

5.3 Implementation of HOTMA Regulations

- Now vs later: treatment of SNT distributions as income. Will only interest be counted? Dividends? No clear answers
- Full mandatory compliance with HOTMA for HUD Multifamily programs is set for January 1, 2027, to allow HUD to finalize software systems like TRACS and update required forms.
- See: PIH_2026-15 https://www.hud.gov/sites/default/files/hudclips/documents/PIH-2026-15.pdf

5.4 Inconsistent Implementation in the Meantime

- Varying reports of local agencies following HOTMA or pre-HOTMA rules.

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6. Trump Accounts (TA)

6.1 What Are Trump Accounts?

https://www.irs.gov/trumpaccounts

6.2 Who Is Eligible?

- The child must be under 18 years old at the end of the calendar year when the account is opened.
- The child must have a valid Social Security number.
- No income limits.
- No earned-income requirements.
- Non-citizen children with a valid Social Security number can still qualify for an account.
- Only one TA is permitted per child.

6.3 Who Can Establish a TA?

- Parents;
- Guardians; or
- Others who are authorized to establish a TA for an eligible child.

6.4 Who Contributes?

- The federal government will make a one-time $1,000 contribution for each eligible child's account.
- The child must be born between January 1, 2025, and December 31, 2028.
- Authorized contributions from individuals, any other third parties, and employers are allowed up to $5,000 per year (indexed for inflation after 2027).
- Employers can contribute up to $2,500 per year toward an employee's or dependent's TA.
- Funds must be invested in certain mutual funds or exchange-traded funds that track a U.S. stock index such as the S&P 500.

6.5 Withdrawal and Use

- Generally, money cannot be withdrawn before the year the child turns 18 ("growth period").
- After that point, the account is treated like a traditional IRA with similar tax rules.

6.6 SSA Treatment During the Growth Period

SSA POMS SI 01120.250 — Trump Accounts (TA)
https://secure.ssa.gov/poms.nsf/lnx/0501120250

Growth Period: Prior to January 1 of the year the TA beneficiary attains age 18.

- The entire value of a TA is not considered a resource for SSI purposes.
- Distributions from the TA generally are not permitted.

The following do not count as distributions:

- Rollover to another TA during the growth period;
- ***Rollover to an ABLE account permitted during the calendar year the TA beneficiary turns age 17;***
- Removal of excess contributions over the annual limit; and
- Distributions upon the death of the TA beneficiary.

6.7 Contributions to TA

- Generally not considered income.
- However, a TA beneficiary cannot avoid income counting by direct depositing funds into a TA.
- Representative Payees cannot arrange to have beneficiary's Social Security or SSI payments paid via direct deposit into a TA, as Representative Payees generally

would not be able to use the benefits to provide for the beneficiary's current needs.

6.8 SSA Treatment During the Post-Growth Period

Post-Growth Period: Beginning January 1 of the calendar year the TA beneficiary attains age 18.

- TA is a countable resource.
- The value of the TA is the amount of money that the TA beneficiary can withdraw from the TA after any penalty for early withdrawal (i.e., early distribution tax).
- Distributions of TA funds are not income, but a conversion of a resource.
- Contributions to a TA are income or a conversion of a resource, depending on the source of the contribution.

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7. SNA's Latest Legislative Efforts

7.1 Child Disability Benefits Fairness Act

Childhood Disability Benefits Fairness Act (H.R. 9846)
https://www.govtrack.us/congress/bills/119/hr9846

- Introduced by Rep. Debbe Dingell.
- Now seeking Republican co-sponsor.

7.2 Assigning Federal Pensions to d4A SNTs & Pooled Trusts

- Bill anticipated to be introduced by Sen. Wyden and Sen. Grassley either by the end of the year or at the beginning of the new Congress.
- It amends three separate federal retirement systems to allow the SNT payment election:
    - Civil Service Retirement System (CSRS);
    - Federal Employees' Retirement System (FERS); and
    - Foreign Service Retirement and Disability System.

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8. Social Security Administration and Trusts

8.1 Potential Use of AI to Review Documents

Artificial Intelligence at SSA
https://www.ssa.gov/ai

SSA Enterprise AI Strategy
https://www.ssa.gov/ai/policy/SSA%20Enterprise%20Artificial%20Intelligence%20Strategy%20Report.pdf

8.2 Concern Over Recent Challenges on Pooled Trusts

1. Concerns regarding documents with previous precedents in the system.
2. Investment Duties POMS SI 01120.225.D
   https://secure.ssa.gov/apps10/poms.nsf/lnx/0501120225
3. Policy on Use of For-Profit Entities:

If a non-profit association employs the services of a for-profit entity, the non-profit association must maintain ultimate managerial control over the trust.

The for-profit entity may handle certain trust functions on behalf of the non-profit association; however, the use of a for-profit entity must always be subordinate to the non-profit managers of a pooled trust under section 1917(d)(4)(C).

For example, the non-profit association must be responsible for:

- *Determining the amount of the trust corpus to invest;*
- *Removing or replacing the trustee; and*
- *Making the day-to-day decisions regarding the health and well-being of the pooled trust beneficiaries.*

***Note:** This list is not intended to be exhaustive. These are a few examples of the type of authority that must vest in the non-profit association.*

4. Using Funds for Legal Counsel: **POMS SI 01120.201.F.4**
   https://secure.ssa.gov/poms.nsf/lnx/0501120201

This provision addresses the sole-benefit rule and expressly permits reasonable costs associated with investment, legal, or other services rendered on behalf of the individual with regard to the trust.

See also:

SSA - POMS: PS 01825.025 - Michigan - 05/18/2018

5. Precedents "Disappearing" From System
   Not all precedents are found in the PS section of the POMS:
   https://secure.ssa.gov/poms.Nsf/lnx/1601825000
   Some organizations are reporting they can no longer be found.

8.6 True Link Transfers Being Counted as Income

- 2026 report that a local SSA office in California was counting all True Link transfers as income.

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9. Extras — Worth a Mention

9.1 HCBS Impacts Tracker Project

George Washington University, along with HSRI, ATI Advisory, and the UMass Boston LTSS Center, have launched the **HCBS Impacts Tracker Project**, looking at how states are implementing federal policy changes (including those under H.R. 1/OBBBA) in their HCBS systems and the impacts of those changes on people with disabilities and older adults.

There is a project webpage where you can regularly check the tracker. They will be updating it every two weeks and will note on the webpage when it was last updated:

https://hpmmatters.publichealth.gwu.edu/HCBS-impacts-tracker-project

1 OBBBA: Where Are We Now?

Interim Final Rule on community engagement requirements for Medicaid expansion adults

138% FPL

Expansion adults (about $22,025/yr, single). Not SSI or HCBS waiver eligibility.

Jan 1, 2027

Deadline for states to implement work reporting requirements.

80 hrs / month

Work, volunteering, or half-time study, or earnings of about $580/month.

Categorical exemptions

- **Medically frail:** condition must "significantly impair" ability to comply (blind or disabled per SSA § 1614; SUD not in 5+ year recovery; disabling mental disorder; disability impairing ADLs; serious or complex medical condition).
- **Caregivers:** parents, guardians, caretaker relatives, and family caregivers of a child 13 or under or a disabled individual.
- **Also:** pregnant and postpartum individuals, and more.

Caregiver definitions

- **Caretaker relative:** blood, adoption, or marriage; lives with and is primarily responsible for care. States may expand.
- **Family caregiver:** regular, non-incidental help as a resident, a nonresident relative, or a non-relative at 80+ hrs/month.
- **Disabled individual:** ADA definition (28 C.F.R. § 35.108), any age; need not be Medicaid eligible on a disability basis.
- **Hardship:** hospitalization, medical travel, disaster declarations, high local unemployment.

Litigation: Massachusetts v. Oz

- **Parties:** 26 states and D.C. challenge the IFR in D. Mass.
- **July 30, 2026:** Judge Stearns denied a preliminary injunction; no irreparable harm since CMS covers 90% of implementation costs.
- **Status:** merits not decided; case continues.
- **Narrowing issue:** states must verify not just a condition, but that it "significantly impairs" ability to work.

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2 New Provider Tax Limits

How states finance their share of Medicaid is getting harder

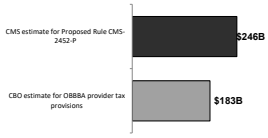
What are provider taxes?

Mandatory fees states place on hospitals, nursing homes, and managed care organizations to help finance the state's non-federal share of Medicaid.

CMS actions after OBBBA

- **Final Rule:** "generally redistributive" requirement bars provider taxes structured to disproportionately burden Medicaid.
- **Proposed Rule CMS-2452-P (July 21, 2026):** implements H.R. 1's new provider tax limits and goes beyond them.

Federal Medicaid reduction over 10 years ($ billions)



Section 1115 budget neutrality, starting Jan 1, 2027

- CMS Chief Actuary must certify budget neutrality before approval.
- Administrative and indirect costs count for the first time.
- States lose flexibility to cover people or services not otherwise allowed under Medicaid.
- A forthcoming rule is expected to cap waivers at five years.

2

3 End of Temporary Status for Haiti and Other Countries

Workforce consequences for home care, long-term care, and aging services

28%

of direct care workers nationwide are immigrants

Source: PHI Midterm Policy Brief Series, Support Immigrants

Impact on the health care workforce

- Impacts arrive when there is already a shortage of workers.
- Immigrants make up 28% of direct care workers nationwide.

Case in point: South Florida

- NBC Miami reports that revoking TPS for Haitians would create a crisis for South Florida's health care industry.

3

4 Community Integration

Olmstead's integration mandate under pressure

1999	June 18, 2026	July 2026	Sept 23, 2026
Olmstead v. L.C.	**DOJ OLC memo**	**Federal Register notice**	**Texas v. Kennedy**
Unjustified institutional segregation is discrimination under ADA Title II	ADA and 504 do not require the most integrated setting	DOJ to revisit Olmstead guidance after Loper Bright; won't rely on it	N.D. Tex. order vacates community integration provisions of HHS 504 rules

Olmstead requires community services when

- Treatment professionals find it appropriate;
- The individual does not oppose it; and
- It can be reasonably accommodated given state resources and others' needs.

What the OLC memo does not do

- Change the law
- Overturn Olmstead
- Invalidate existing court orders
- Prevent individuals from bringing Olmstead claims

Why it still matters

- OLC opinions bind all executive branch agencies.
- Likely to shift DOJ and HHS enforcement, including existing settlements and agreements.
- HCBS waivers that SNT clients rely on rest on Olmstead.

4

5 Fraud, Waste, and Abuse Initiatives

New scrutiny on so many fronts

46%

of SSA overpayment notices reviewed by the OIG did not meet SSA's own policy requirements

Deficiencies included

- Missing explanation of how and when the overpayment occurred
- Omitted reconsideration and waiver rights
- Inaccurate dollar amounts
- Conflicting or unclear language
- Insufficient detail on calculation methods

Source: SSA Office of the Inspector General, Sept. 4, 2026

Implementation of HOTMA regulations

- **Open question:** how SNT distributions are treated as income, now vs. later. Only interest? Dividends? No clear answers yet.
- **Jan 1, 2027:** full mandatory HOTMA compliance for HUD Multifamily programs, giving HUD time to finalize TRACS and update forms.
- **Reference:** HUD Notice PIH 2026-15.

Inconsistent implementation in the meantime

- Varying reports of local agencies following HOTMA rules or pre-HOTMA rules.

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6 Trump Accounts (TA)

Eligibility, contributions, and SSI treatment (POMS SI 01120.250)

$1,000	$5,000	$2,500	Age 18
One-time federal seed for children born 2025 through 2028	Annual cap on contributions from all sources (indexed after 2027)	Annual employer contribution for an employee or dependent	Growth period ends; then IRA-like tax rules apply

Eligibility and setup

- Child under 18 at end of the year opened, with a valid SSN (non-citizens with an SSN qualify).
- No income or earned-income limits. One TA per child.
- Opened by parents, guardians, or others authorized.
- Invested in funds tracking a U.S. stock index; generally no withdrawals before 18.

SSI: growth period (before year of age 18)

- Entire TA value is not a resource.
- Not distributions: rollover to another TA, removal of excess contributions, death of beneficiary, and a rollover to an ABLE account in the year the beneficiary turns 17.
- Contributions generally not income, but benefits can't be sheltered by direct deposit; rep payees may not route SSA or SSI payments into a TA.

SSI: post-growth period (from Jan 1 of year of age 18)

- TA is a countable resource.
- Value = amount withdrawable after any early distribution tax.
- Distributions are a conversion of a resource, not income.
- Contributions are income or a resource conversion, depending on source.

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7 SNA's Latest Legislative Efforts

Two bills to watch

H.R. 9846

Childhood Disability Benefits Fairness Act

- **Sponsor:** Rep. Debbie Dingell.
- **Status:** introduced; now seeking a Republican co-sponsor.

Wyden / Grassley

Assigning Federal Pensions to (d)(4)(A) SNTs and Pooled Trusts

- **Timing:** expected by year end or at the start of the new Congress.
- **Effect:** lets federal retirees elect to direct pension payments to an SNT, across three systems:

CSRS | **FERS** | **Foreign Service RDS**

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8 Social Security Administration and Trusts

AI review, pooled trust challenges, and field office inconsistency

Potential use of AI to review documents

- SSA has published an Enterprise AI Strategy.
- AI may be used to review trust documents.

True Link transfers counted as income

- 2026 report: a local California SSA office counted all True Link transfers as income.

Concern over recent challenges on pooled trusts

1. **Documents with prior precedents**
   Concerns about documents that already have precedents in the system.
2. **Investment duties**
   POMS SI 01120.225.D
3. **Use of for-profit entities**
   Non-profit must keep ultimate managerial control: investing corpus, removing trustees, day-to-day beneficiary decisions.
4. **Funds for legal counsel**
   POMS SI 01120.201.F.4 permits reasonable investment, legal, and other trust-related costs under the sole-benefit rule.
5. **Precedents "disappearing"**
   Not all precedents are in the POMS PS section; some organizations can no longer find theirs.

8

9 Extras: Worth a Mention

HCBS Impacts Tracker Project

Tracking how states implement federal policy changes, including H.R. 1 / OBBBA, in their HCBS systems, and what those changes mean for people with disabilities and older adults.

Project partners

George Washington University | **HSRI**

ATI Advisory | **UMass Boston LTSS Center**

Every 2 weeks

The tracker is updated biweekly, with the last-updated date posted on the project page.

hpmmatters.publichealth.gwu.edu/HCBS-impacts-tracker-project

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