



## FEATURE: ESTATE PLANNING & TAXATION

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# Planning for an Individual With Asperger Syndrome

It requires an understanding of the unique nuances of this disorder

**A**sperger syndrome (AS) is a neurological condition on the autism spectrum. It's a pervasive developmental disability that affects an individual throughout his life. Planning for anyone living with AS requires an understanding of its unique nuances. That way, practitioners can effectively interface with AS clients and help them with estate and financial planning.

AS has a genetic basis, so it often can be seen throughout generations of an extended family. The prevalence of AS in a family is important to planning. For example, if a client has a child or grandchild with AS, the client may consider planning only for that child. But, given that AS is hereditary, that limited planning could be a mistake, and practitioners should consider planning steps for future descendants who may also have AS.

### Prevalence of AS

The incidence of AS generally is somewhat uncertain, as the rate of diagnosis varies significantly. For example, clinicians in some states are more likely to give the diagnosis than in others, even when the test results are comparable. Acknowledging this issue, the Centers for Disease Control and Prevention estimates that approximately one in 68 individuals in the United States are on the autism spectrum.<sup>1</sup>

The Asperger/Autism Network estimates that 50 percent of people, especially women, and those aged 30 and older, are living with AS but haven't been diagnosed.<sup>2</sup> It's thought that three to four times as many males as females have AS. Females with AS can present differently from males with AS. Females seem to be able to hide their differences and difficulties better than their male counterparts. Because of their ability to "pretend to be normal," females are often undiagnosed or misdiagnosed as having mental health issues.

### Individual Variation

Those with AS can differ greatly from one another in terms of the traits they exhibit. Planning is thus difficult, as one can't predict the ultimate level of independence a given individual with AS may achieve and when in life it may occur. While there are common traits, practitioners must be particularly careful to understand the unique situation, strengths and challenges of each individual for whom they're planning. Standard planning formulas, based only on the fact that a client has AS, or has a family member with AS, won't be effective. For example, an intense special interest in mathematics could be adaptive for some individuals in some situations, but a social deterrent in other situations. Perfectionism can make someone an excellent editor or code writer, and/or a difficult spouse or parent.

This variability represents a significant challenge to practitioners. While holding any gifts or bequests in trust might be advisable if the gifts or bequests aren't essential, the nature of that trust may have to vary quite significantly from one individual with AS to another, and even for the same individual over time. Flexibility in the operation and management of a trust is key.

### Traits to Consider

Understanding the wide continuum on which many AS traits may range, here are some of those traits that



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practitioners may need to address in planning:

- **IQ.** Most individuals living with AS have average range IQs. Some with AS, however, have very high verbal IQs and can be extremely articulate. However, verbal ability and IQ don't necessarily translate into an ability for the individual with AS to function effectively or live independently in the world.

**Impact on planning.** As will be discussed, professional advisors can't assume "one size fits all" with the AS community. They must work with the AS individual and other professionals to tailor the plan based on abilities.

- **Social and other challenges.** It's common for an individual with AS to have atypical sensory processing, difficulty with social communication and difficulty with executive functioning. The rate of mental health issues, especially anxiety and depression, is higher than average for individuals with AS. Intelligence sometimes results in family and others having higher than reasonable expectations for an individual with AS, yet individuals with AS may not meet those expectations because they struggle with social situations. Those who don't understand AS may misjudge an individual with AS, assuming he's stupid, thoughtless or lazy, none of which may be correct. As a result of these and other factors, many individuals living with AS have difficulty in school, employment, friendships and relationships. In spite of these challenges, some living with AS can be highly successful, completing high school, college and earning advanced degrees. Some are successfully employed, while others, despite their high IQ, are unable to hold a job.

**Impact on planning.** The professional advisors may need to make specific accommodations when working with a person with AS or that person's family. These will be discussed later in the article.

- **Atypical development timetable.** Children and teens with AS usually develop on a slower timeline than their peers. They may be less mature than their peers. While neurotypical (non-AS) adults may find their first relationships and jobs in their

20s, those with AS may not reach those milestones until ages 30 to 35.

**Impact on planning.** When working with a family that includes a person with AS in their teens or 20s, it's important to build flexibility into the plan. The full potential of that individual may not be fully evident until later in life.

- **Work characteristics:** Keen senses, strong powers of

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observation and a perfectionist's attention to details are common to many with AS. An intense special interest in the sciences, technology, the humanities or the arts can lead to employment and solid contributions to scholarship and human welfare. Other characteristics that may be relevant to career results might include: excellent rote memory, a strong work ethic, an ability to focus intently and for a long time on a topic or task, an ability to work alone and an ability to do a routine task without boredom.

**Impact on planning.** Professional advisors will want to build a "safety net" for people with AS in the event their intense special interest doesn't align with an employment opportunity. (See below for examples.) However, it's possible that the "net" is never used.

- **Personal traits.** Many with AS may have traits such as: honesty, a passion for justice, an ability to be unusually creative and to generate original thinking. On the other hand, those living with AS often



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have difficulty acquiring and maintaining long-term friendships, even when strongly desired, due to their difficulty with social situations and interpersonal communication. An individual with AS may have difficulty understanding social contexts and behaviors. Perceiving the intentions or emotions of other individuals doesn't come naturally or intuitively, but has to be learned cognitively and with social coaching. Those living with AS commonly have a tendency to miss or misinterpret nonverbal cues—which constitute the bulk of social communication—including facial expression, body language and vocal intonation. They may be poor at social chatter (small

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talk) and appear awkward, rude, uncommonly blunt, insensitive or disinterested in others, causing their peers to avoid them. These unusual or unexpected ways of behaving can have a profound detrimental impact on their social lives.

**Impact on planning.** Many practitioners might presume that someone with AS should never be named as a trustee. But, for individuals with significant success and capabilities, a co-trustee role may be feasible. For example, an individual with AS who is intellectually bright and even quite successful in terms of employment could be named as a co-trustee of a trust for his benefit so long as another co-trustee can safeguard the person with AS from being taken advantage of financially. Practitioners should exercise caution in naming a friend or family member of the individual with AS as trustee because the individual with AS may not be able to determine if that friend or family member is taking advantage of the situation. Perhaps an institution could be used as a trustee or co-trustee, or perhaps a trust protector can be named to provide an extra check on the trustee's activities. Many trusts rely on the beneficiary's interest to temper inappropriate activity by a trustee. A beneficiary

with AS, even an intellectually accomplished one, may not be able to do this. On the flip side, many individuals with AS shouldn't have their wishes disregarded by a trustee in making trust decisions. Because many with AS are quite capable, they should be consulted more than some trustees may realize. Perhaps the trust instrument should encourage the trustee to consult with the beneficiary to the extent the beneficiary can provide input.

- **Sensory regulation.** Individuals living with AS may experience unusual sensitivity to sights, sounds, smells, tastes or textures. For example, some individuals with AS are very sensitive to fluorescent lighting or may be sensitive to certain noise, touching by other people or the texture of food. For example, taking a shower might feel like shards of glass falling on their scalp. For many, eye contact is actually painful. Some with AS have difficulty paying attention or switching attention from one activity to another, as well as struggling with organization and prioritization of their time, materials and activities. They find it hard to initiate, plan, prioritize and complete tasks on deadline. Individuals with AS can be very resistant to change, as change provides them significant anxiety.

**Impact on planning.** Recognizing the difficulties with change that typical clients have, practitioners representing someone living with AS should endeavor more so to have family meetings and help the individual better anticipate life transition points.

### Checks and Balances

As explained above, a common trait of those living with AS is difficulty interpreting common personal interactions. As a result, an individual with AS may be especially vulnerable to financial or other abuse, and the practitioner needs to take steps to protect him.

Checks and balances for each phase of planning are critical. Consider forming a planning team so that independent advisors, such as a CPA, attorney and financial advisor, can review and monitor each other. Include a provision in trusts naming a care manager who's familiar with AS, as well as a relative of the individual with AS who's truly looking out for that individual's best interests. The care manager can educate other advisors on the nuances of planning for the client with AS, as well as help interface with that client. Use trusts with



an independent trustee to monitor what the individual with AS does.

Trustees alone, however, aren't adequate safeguards. For example, if a family member or friend is named as trustee, he too must be monitored to assure he's not pilfering the funds intended for the beneficiary living with the challenges of AS. Don't assume that all institutions are going to act appropriately either. Consider appointing a trust protector with the power to terminate and replace trustees. If a child with AS has sufficient capacity, he might hold this power. Also consider giving independent family members a power to terminate and replace trustees. An individual with AS may be better served with an institutional trustee (especially an institution with experience dealing with AS), as well as with a family member who has the right to fire and replace the trustee.

### Guardianship

A full guardianship won't be necessary or appropriate for many living with AS due to their average to above average intelligence and ability to make their own decisions (whether good or bad). For others with AS, a guardianship might be advisable. However, when a practitioner pursues guardianship for an individual with AS, the practitioner must exercise great care so that the appointment of a guardian doesn't result in unduly limiting the freedoms of the individual with AS, especially if other checks and balances might suffice.

### Young Child With AS

Have a flexible plan for a young child with AS. The child may require the classic special needs planning path, have problems with employment and not be self-sufficient financially. On the other hand, the child may develop and become financially very successful. As the child ages, it may become apparent what financial/work status the child will have, and planning can then become more tailored to that child's specific situation. Given the wide range of possible outcomes, perhaps including a standby special or supplemental needs provision with a trigger mechanism to activate if appropriate may be advisable. For some children, a supplemental needs restriction may prove an unfair and unwarranted limitation.

In all cases, however, advise the parents that they need to be realistic about their AS child's life-long challenges. Individuals with AS may have periods of

employment, strong personal relationships and/or relative happiness, followed by stretches of unemployment, lack of personal attachment and/or deep unhappiness. A life with AS often isn't a linear path, although long-term progress is common. Above all, parents and their financial professionals will need to create a safety net for the individual with AS that can supplement the independent progress he makes.

The financial planning itself must be kept quite flexible and robust. The parent, for example, might consider putting in place a life insurance plan that can assure the proper level of financial assistance to the child in the future if needed, but include sufficient flexibility to

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modify that planning as the situation becomes clearer. Perhaps the parent can use a term insurance with conversion options. In this way, if the child grows and becomes financial independent, then the term might be allowed to lapse. If the child ends up on a less independent path, then the parent might choose to convert that term insurance and assure adequate protection on a permanent basis for that child.

The parent and the advisors might implement a "laddered" term insurance plan. In this structure, the parent could purchase term policies with various terms of guaranteed premium payment (for example, 15 years, 20 years and 30 years). As the guaranteed term period for each policy nears, the parent can assess his AS child's situation. The parent can then determine if a conversion is necessary or, alternatively, if the remaining coverage and term lengths are sufficient or if coverage can lapse.

It may also be worthwhile to use survivorship or "second-to-die" life insurance. With this product, the death benefit is paid to the beneficiary on the death



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of the second parent. This technique is common with severely disabled dependents who have special needs trusts (SNTs) established for them, as will be the case for some with AS. With the survivorship life insurance, the trust is funded precisely when it's needed the most, and, if constructed properly, avoids payment of estate and income taxes.

Other factors parents of a child with AS should consider:

- When parents are planning for their own retirement, they'll need to factor in the potential of having additional expenses for their adult child with AS. Parents

An adult client with AS who functions at a high level might still be at risk for financial abuse.

should have additional cash reserves in retirement and develop asset withdrawal strategies that assume essential expenses for their child. Because of the need for flexibility given the level of dependency of the child with AS, parents should be careful not to overload their retirement portfolio with products that generate a rigid stream of income or that carry high switching costs (such as surrender charges).

- When planning for pre-college education, parents should be very observant during the child's formative years to ensure the proper fit among the school, the individual education program (if there is one) and the child. In particular, there should be an emphasis on social skill development and skills related to executive function. There's often an additional need for occupational therapy and physical therapy. Parents would be well advised to build expenses into their plan for neuropsychological evaluations, planned outside school activities, professional advocates and, in many cases, private education.
- When planning for college education, parents shouldn't assume with certainty (as they might with a neuro-typical child) that the child with AS will attend a 4-year accredited college or university.

- Parents should monitor the dollars they put into a Section 529 college account because assets not used for college expenses are both taxed and penalized. Other considerations include if the parents have other children who are neuro-typical or if the parents have strong reason to believe that the child with AS has the ability to thrive in school (perhaps because he can study his particular passion in an accredited institution). To ensure flexibility, parents of an AS child may want to establish a taxable, non-qualified account with an asset allocation consistent with the time frame for the child's education. Parents should hire a college consultant who specializes in children with disabilities.
- Parents should become familiar with the rules associated with claiming Social Security Disability Insurance (SSDI) for young adults. It's not uncommon for an individual with AS to have a checkered work history that's characterized by periods of work, followed by periods of unemployment. Depending on the severity of the AS symptoms, as well as other health factors, the young adult with AS may qualify for SSDI. The definition of "disability" under SSDI is the inability to engage in any substantial gainful activity because of a medically determinable physical or mental impairment that's either expected to result in death or to last for a continuous period of at least 12 months.

In addition, the individual with AS must also have the requisite number of work credits. In 2016, workers receive one credit for every \$1,260 of wages or self-employment income. The maximum number of work credits a worker can receive annually is four. The required number of work credits to receive SSDI is:

- Disabled before age 24: Able to qualify if the individual earns six credits in the 3-year period ending at onset of disability.
- Disabled between ages 24 and 31: Able to qualify if the individual earns credits for at least half of the time between age 21 and onset of disability.
- Disabled between ages 31 and 42: Able to qualify if the individual earns 20 credits.

If the individual with AS is unable to build up his own work history, he may still be able to receive an SSDI



monthly benefit. When one of the parents retires, dies or becomes disabled, the individual with AS can receive a benefit based on his parent's work history, provided that the person with AS meets the definition of disability stated above.

For these reasons, the parents should also be vigilant about checking that the Social Security Administration accurately tracks their earning history.

- For severe cases, parents of an individual with AS should familiarize themselves with other government programs available to the special needs community (including SSI and Section 8 housing vouchers).

**Irrevocable trust planning.** For a younger child, special needs planning may need to be left open as an option. If irrevocable trusts are created as part of a parent or other benefactor's plan, consider SNTs that trigger if and only if the child receives government aid. Such an SNT wouldn't apply if the child were to achieve a greater level of success, but be available at a future date should the child qualify for governmental assistance.

If a practitioner is contemplating a life insurance or other trust with annual demand (*Crummey*) powers, the child with AS could be excluded from being a power holder or beneficiary for *Crummey* power purposes should the SNT be triggered. A more flexible option is to provide in the trust instrument a right or power to the trustee or grantor to exclude any beneficiary from the class of *Crummey* power holders. In that way, if the *Crummey* power is needed, it will be available if the child hasn't had to qualify for governmental assistance. Practitioners should bear in mind that at the time of this writing, there are governmental proposals to cap *Crummey* powers in trusts at \$50,000 per donor, so the issue may become academic.

### Adult Client With AS


Too often, practitioners assume that AS is a challenge that only has to be addressed for a client's child. This is too limiting and factually inaccurate. Clients themselves may have AS and need a full range of planning services. Practitioners should take steps to understand the challenges the particular client has and to tailor planning.

#### General considerations:

- Executive function challenges are common. The client may not be able to stick to a budget or keep track

of dates bills are due and may have challenges with daily management of cash flow.

- The client may be painstakingly detailed to the point it exasperates practitioners endeavoring to help, thereby stalling important progress in the planning process.
- It may be impossible to tell a client with AS what actions to take or how to modify his fiscal behaviors. Some won't compromise. The practitioner needs to understand that he may not be able to change behavior without assistance from a care manager or family member.
- Medical expenses are likely to be higher than for other individuals similarly situated so that this should be factored into any financial forecasts.
- Practitioners should be on the look out for erratic spending behaviors (such as for a particular passion), incidences of poor financial decision making and giving money to friends/significant others.

An adult client with AS who functions at a high level might still be at risk for financial abuse. That client might be well served by funding a revocable trust naming himself as co-trustee with an institution. In that way, the institution can help monitor all of the individual's finances to minimize the risks of financial abuse. But, for a client with AS serving as his own co-trustee, there should be relatively little imposition or limitation imposed on his personal financial freedoms. 

### Endnotes

1. Autism and Developmental Disabilities Monitoring Network Surveillance Year 2010, Principal Investigators; Centers for Disease Control and Prevention, Jon Baio, collaborator.
2. Christopher Gillberg, *British Journal of Psychiatry* (1998) at pp. 171, 200-209.