

AGING WISELY

Planning for a child with Special Needs

Americans, including those with disabilities, are living longer than they did in years past. According to one count, 730,000 people with developmental disabilities are living with caregivers who are 60 or older. This figure does not include adult children with other forms of disability nor those who live separately, but still depend on their families for vital support.



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When these caregivers can no longer care for their children due to their own disability or death, the responsibility often falls on siblings, other family members, and the community. In many cases, expenses increase dramatically when care and guidance provided by parents must instead be provided by a professional for a fee.

Planning by parents can make all the difference in the life of the child with a disability, as well as his or her siblings who may inherit the responsibility for caretaking (on top of their careers, caring for their own families and, possibly, ailing parents). Any plan should include at least the following three components:

■ A plan of care that carefully establishes where the child with special needs will live, who will be responsible for assisting the person with special needs with decision making and who will monitor the person with special needs' care. It will help everyone involved if the parents create a written statement of their wishes

for their child's care. They know him or her better than anyone else. They can explain what helps, what hurts, what scares their child (who, of course, is an adult), and what reassures him or her. When the parents are gone, their knowledge will go with them unless they pass it on.

■ At least one type of special needs trust. When a parent leaves funds at death to a disabled child, this generally should be done in the form of a trust. Trusts set up for the care of a disabled child generally are called "supplemental" or "special" needs trusts. There are three main types of special needs trusts: the first-party trust, the pooled trust and the third-party trust. All three name the person with special needs as the beneficiary, but differ in significant ways. All three trusts are intended to preserve the child's government benefits while preserving the trust funds for needs other than food and shelter.

The first-party trust, which holds assets owned by the disabled person (i.e., litigation proceeds), requires that assets remaining in the trust at the child's death reimburse the government for benefits it paid for the child. The pooled trust is an accumulation or "pool" amounts of funds belonging to numerous individuals, which is centrally managed and invested. At the child's death, the assets must remain in the trust for other beneficiaries to use. The third party trust consists of assets owned by someone other than the disabled person, such as a parent or aunt or uncle. At the child's death assets in a third-party trust can pass to anyone named by the person who

created the trust.

Regardless of the type of trust used, it is critical to select an appropriate trustee. Most people do not have the expertise to manage a trust, and a professional trustee may be a wise choice. For those who may be uncomfortable with the idea of an outsider managing a loved one's affairs, it is possible to simultaneously appoint a trust "protector" who has the power to review accounts and to hire and fire trustees, and a trust "advisor" who instructs the trustee on the beneficiary's needs.

■ Life insurance. A parent with a child with special needs should consider buying life insurance to fund the supplemental needs trust set up for the child's support. What may look like a substantial sum to leave in trust today may run out after several years of paying for care previously provided by a parent. And if both parents are alive, the cost of "second-to-die" insurance—payable only when the second of the two parents passes away—can be surprisingly low.

If readers have questions on estate planning or elder law issues, please write to mhjerpe@crflp.com and I will try to answer the questions in future columns.

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STRAIGHT UP THE MIDDLE

It's time to act on NFL's black eye

One thing I truly dread about the end of baseball season is that our TV seems to host an hours-long and seemingly never-ending football game on Sunday afternoons and evenings. I will watch the Patriots but usually spend the rest of the evening mocking the commentators or "the waitin' on waitin' on Sunday night" dance that Carrie Underwood does every week in a



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shrinking sparkly dress. This week's featured late game was the Dallas Cowboys v. Denver Broncos and one of the commentators read an awkward statement at the beginning of the program about how the new details that have emerged from Dallas player Greg Hardy's assault on his girlfriend. Long story short, he beat her up and then paid her off so even with a mountain of evidence against him that included graphic photos and several witness statements, his suspension was reduced to a measly four games and he's once again making millions of dollars to play a game.

Sadly, Greg Hardy is just the latest in a long line of professional athletes who brutally assault their partners and are not behind bars. Ray Rice, last year's poster child for assault and battery, was seemingly blacklisted from the NFL after the film of him dragging his unconscious fiancé by her hair became widely available but he has actually been using the media spotlight around Hardy to let people know that he is ready to play in 2015(!). The NFL and the various teams that have

been involved with these issues have been complicit in protecting these players and seem intent to ride out the scandal rather than get out in front of the issue and say "no more." While I am sure that their existing contracts protect these players, now would be a good time for the NFL to issue a policy that does not tolerate domestic abuse from its players. By not taking a strong stand, they are not only setting a precedent for future cases but telling a generation of young men that they can get away with whacking someone if they can afford pay them off.

In the absence of a zero tolerance policy on domestic abuse, I think that fans of football should show their disgust by making a different choice when tempted by NFL merchandise. A piece of every dollar spent on that jersey supports policies that are rewarding and protecting violent men. Unless the league feels a tremendous amount of pressure from fans and their bottom line, they have no real impetus to change their behavior and next season we'll have another Ray Rice or Greg Hardy to talk about.

Cara Cromwell is a public affairs consultant with more than twenty years experience managing issues campaigns for corporations, non-profits, associations, coalitions and candidates on both sides of the aisle. She believes that in politics—and baseball—game changing action occurs in the middle, creating opportunity on the ball field and compromise and coalition-building in the halls of power. Visit her blog, Straight Up The Middle, at straightupthemiddle.blogspot.com and follow her on Twitter @cmcromwell.

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