

# SECURE

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## A Journey of Joy and Independence in the Community

A common sentiment from mothers who have a child with an intellectual or developmental disability is that it makes them stronger, more self-reliant parents. Pat Hornbecker has four children, and her oldest (and only son) Joseph was born with Angelman Syndrome. As she began her path of discovery of what it would take to help her son be more included in their community, she learned the importance of persistence, asking questions, and self-confidence.

From the time that Joseph was an infant, Pat sought out networks and resources in her San Francisco community that she could learn from—and quickly became connected to The Arc, which offers services to a broad spectrum of people with intellectual and developmental disabilities. With The Arc’s help, her family established creative and unexpected goals in

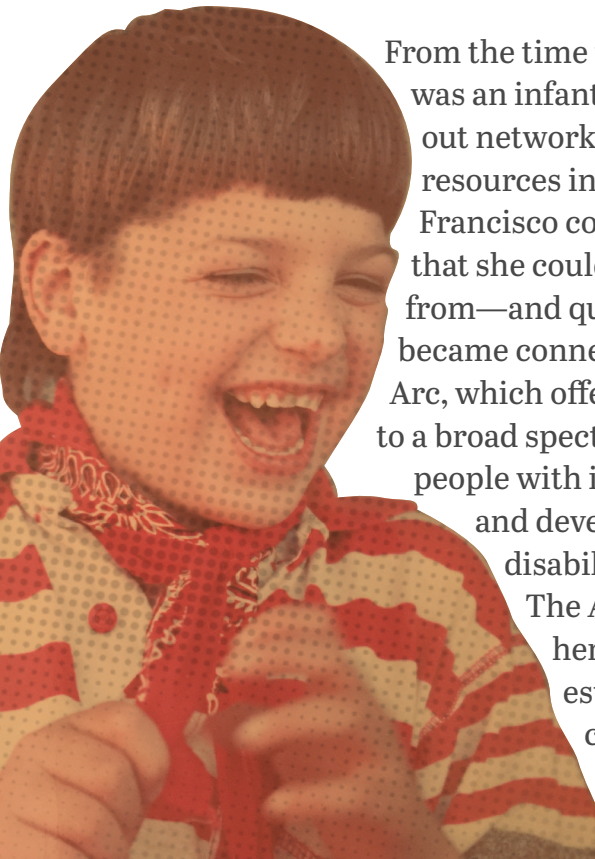
Joseph’s IEP and a special supported employment initiative that got Joseph out in the community. With one-to-one support, he participated in everything from un-hanging clothes at a local Nordstrom to assisting at a food bank and even cleaning up graffiti. All of this resulted from learning to ask what Joseph liked, involving him in decisions, and never underestimating his ability to be a part of the community around him.



“I didn’t keep him in a cocoon seeing the same people and things over and over. I [told him I] understood that when your sisters pass you by, it can be particularly hard. So, I created connections and found ways to keep him in an environment where he could contribute and relate to the growth of others around him. Obviously, this helped his growth too.”

Over time, Pat became a force to be reckoned with as she worked to promote and protect the rights and inclusion of Joseph and others like him across the country. She stayed involved and aware of what services and supports were available at the local, state and national level—contributing to and speaking for The Arc of San Francisco and The Arc of California. She even served on The Arc’s national board of directors.

*story continued on page 2*



## Planning With Special Needs Trusts

BY LAUREN G. DELL, ESQ.

If you have a family member that receives or may need Medicaid benefits, you may have a desire to support them with supplemental funds. Unfortunately, Medicaid eligibility can work like financial aid for college—the more assets that a candidate has at their disposal, the harder it is for them to qualify for aid.

If you are in this situation, you may want to consider creating a **special needs trust** for the Medicaid recipient. These trusts can help support beneficiaries, without disqualifying them from Medicaid for having too many assets. They can also help the beneficiary qualify for Supplemental Security Income (SSI).

There are two general categories of Special Needs Trusts. **First-party special needs trusts** are created by Medicaid-eligible individuals with their own assets. When someone is already receiving Medicaid, a First-Party Special Needs Trust can be used to manage funds received from an inheritance or court settlement. Each state has its own rules governing the use and management of these trusts, but Federal law mandates that they include the following:

- The trust for a minor must be established by a parent, grandparent, guardian or the court. The beneficiary's assets must be used to fund the trust.

- The trust must be irrevocable.
- The beneficiary must be less than 65 years of age when the trust is established.
- At the beneficiary's death, any funds paid over time by Medicaid on behalf of the beneficiary must be paid back to the state Medicaid agency, up to the entire value of the remaining trust assets.

**Third-party special needs trusts** are set up—and funded—by individuals other than the Medicaid recipient, often a parent or grandparent. Contributions to these trusts are gifts from the donor and are subject to the same gift and estate tax rules as contributions to traditional trusts. Assets in these trusts can be used to supplement Medicaid benefits, but unlike first-party trusts, the assets do not have to be used to reimburse the Medicaid agency at the beneficiary's death, so families can choose to distribute assets, for example, to other family members or to a charity. In addition, these trusts can be established for someone who is more than 65 years of age and are generally subject to less oversight by state governments.

Often, the choice between establishing a third-party or first-party special needs trust depends on your family's assets and how they are owned. Families should consult with their financial, legal, and tax advisors to determine which structure will best meet their needs.

Want to know more about special needs trusts? Please contact The Arc's Development Department at [plannedgiving@thearc.org](mailto:plannedgiving@thearc.org) or 202.534.3713. Families are encouraged to consult with their tax or financial advisor.

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## Empower People With Disabilities To Make Their Own Health Care Decisions

Established in 2015, The Arc's Center for Future Planning aims to support and encourage individuals with intellectual and/or developmental disabilities (I/DD) and their families to plan for the future. The Center provides reliable information and assistance to individuals with I/DD, their family members and friends, professionals who support them, and other members of the community on areas such as person-centered planning, decision-making, housing options, and financial planning.

In partnership with The Arc of Massachusetts, The Arc has developed a new resource titled "A Letter for My Doctors," to help people with I/DD describe how and when they want help making health care decisions. The letter can be used to explain:

- How the person acts when he/she is upset, worried, or confused
- What a health care provider can do if the person is upset, worried, or confused
- When the person wants help making health care decisions
- Who the person wants to help them make health care decisions

Visit The Arc's Center for Future Planning at [futureplanning.thearc.org](http://futureplanning.thearc.org) to learn more about supported decision-making and other alternatives to guardianship.

*continued from cover page*

*"The Arc has been the only system that I could tap into to be able to understand to make the accommodations [and] create the realities I want. The Arc helped me find out what's possible."*

Pat had to search for the resources that met Joseph's needs, since they were often complex. She knew that if she was willing to help train the caregivers, which included creative souls from musicians to skateboarders, with the help of The Arc she could create Joseph's unique support network. Joseph moved to his own apartment when he was 20, and loves being independent. His needs will continue to be significant, but Pat knows The Arc will always be there to provide resources, peace of mind, and new possibilities. With his community and The Arc behind him, Joseph will have the tools to live a joyful, meaningful, and independent life.

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INVESTING IN THE FUTURE

Investing in the Future  
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## Have You Made Your Annual Required Minimum Distribution?

If you are over the age of 70.5 and have an IRA, you  
must make an annual minimum distribution  
(or suffer significant penalties).

If you make the annual distribution to a nonprofit  
(like The Arc) you will not have to pay taxes on the  
withdrawal (up to \$100,000).

You need to transfer the money directly from the IRA  
to the charity for it to count as the tax-free transfer.

LEARN MORE BY VISITING: [thearc.giftlegacy.com](https://thearc.giftlegacy.com)



[bbb.org/charity](https://bbb.org/charity)

The BBB Wise Giving Alliance National Charity Seal carries a lot of meaning for both donors and charities. After undergoing a rigorous evaluation by the BBB Wise Giving Alliance, The Arc is proud to have received their seal for meeting the Standards for Charity Accountability!



**Achieve with us.®**

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