

**The Mission is Possible to Find Quality Residential Care**

Presented by: Jim Caffry, Jim McCarten, and Mark Olson

Stetson Special Needs Planning and Special Needs Trusts Conference  
October 17, 2024

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**3 FATHERS**

**3 FAMILIES**

**3 JOURNEYS**

**ONE GOAL!**

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About Us




**James A. Caffry, Esq.**  
Caffry Law, PLLC  
Waterbury, Vermont

- Father of young adult son with I/DD, ASD
- Special Needs Alliance, Member since 2007
- Riverflow Community, Inc., part of founding group



**James M. McCarten**  
Senior Counsel  
Lindsey & Lacy, PC  
Peachtree City, Georgia

- Father of adult daughter with I/DD, ASD
- A "Tax Nerd" (per Kathryn)
- Special Needs Alliance, Member since 2009
- Practice in both Georgia and Tennessee
- Georgia Department of Behavioral Health and Developmental Disabilities Advisory Council, Region 6, Member since 2018
- Advocate with many Southeast disability organizations



**Mark L. Olson**  
President & CEO  
LTO Ventures

- Father of 2 disabled adult daughters
- Consultant & Project Manager
- 9 projects in 5 states (IN, OH, PA, TX, WI)
- Our own project - **Autumn Hills Village** in Boerne, TX
- Advocate - local, state, federal levels

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## The Need

- **7.39 million** - Individuals in the U.S. with an intellectual or developmental disability (IDD) in 2019<sup>1</sup>
- **11%** - Live in a home of their own<sup>1</sup>
- **72%** - Live with a family caregiver<sup>2</sup>
- **24%** - Live with caregiver aged 60 or older<sup>2</sup>
- **497,354** on waitlists nationally (Texas: 311,532; 18 years for HCS waiver) (Georgia: 7,000+)<sup>3</sup>
- 5 million Direct Care Workers in 2022; **8.9 million more** needed by 2032<sup>4</sup>

<sup>1</sup>In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends Through 2019 report produced by the Residential Information Systems Project (RISP) of the University of MN  
<sup>2</sup>Travis, S.S. et al. (2021). The State of the States in Intellectual and Developmental Disabilities: Kansas University Center on Developmental Disabilities, The University of Kansas. <https://ucdidd.org/kansas/>  
<sup>3</sup>Waste Family Foundation Medicaid HCBS Waiver Program Survey, FY 2023  
<sup>4</sup>WHS. <https://www.washingtonpost.com/news/energy-environment/wp/2022/05/05/direct-care-workers-needed-by-2032/>

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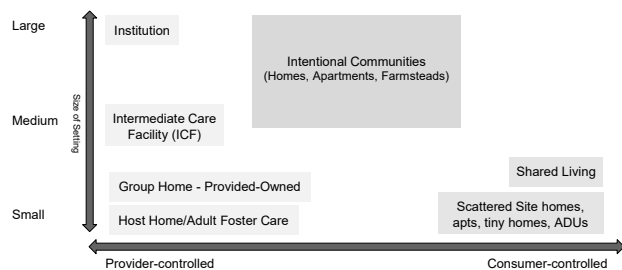
## Factors in the McCarten Housing Journey

- Safety
- Skills already acquired
- Skills we believe can reasonably be acquired
- Supports needed
- Social opportunities (employment is included here)

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## Range of Housing Options Today



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### An Overview of Structural Choices (the legal structuring)

1. If the family or a trust is to own the home and there are roommates, whether employed or paying rent
  - Are tax benefits possible?
  - Want liability protection?
  - Then likely use an LLC.
2. Is nonprofit status beneficial?
  - Medicaid provider preference
  - No income tax is paid (an indirect government subsidy)
  - Access to tax deductible contributions
  - Access to Government and Foundation grants

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### Tax Exempt Issues

1. Private Foundation vs. Public Charity status
  - Mission related revenues are treated as public support
2. Private Benefit/Private Inurement
3. Self-Dealing
4. The Intermediate Sanctions

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### LTSS - Long-Term Supports and Services

- Resident Support Needs
  - 24/7, One-on-One, or High Behavioral Support
  - Moderate, Low, Drop-in, or No Support
  - Memory care
- LTSS Delivery Models
  - Provider-based, agency-based or self-directed rotational staffing
  - Host home / adult foster care
  - Shared living
  - Natural supports / circles of support
  - Remote monitoring
- Funding Options
  - Medicaid HCBS
  - Medicare or other insurance
  - Private pay

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### Medicaid HCBS Waivers - *Fastest 3 minutes in sports*

- Waives certain Medicaid requirements to enable individuals with disabilities, elderly, medically fragile to access Medicaid funding for a range of supports
- SCOTUS 1999 decision - *Olmstead v L.C.* - deinstitutionalization mandate
- CMS Final Settings Rule - CMS-2249/2296-F - and guidance (2014 & 2019)
- Waivers are federal-state share: Settings Rule sets the floor, states can add
- Settings Rule - currently focused on opportunities, experiences, & outcomes
- Eligibility and waiver program differences vary widely across states:
  - Good: Wisconsin IRIS, Arizona IDLA
  - Problematic: Indiana CIH, Pennsylvania Comprehensive, Texas HCS

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### Building Your Own Housing

- Vision, Mission, Core Values/Guiding Principles
  - Who you want to support
  - What is the purpose and desired long-term outcomes
  - What type of housing, common spaces
  - How do you want it to operate
  - Medicaid-eligible or private pay
- Capacity and realistic expectations
- Learn from others - nothing like experiencing settings in-person
- Leverage professionals and people who've done it before
- Broad-based community support

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### Funding to Build Your Own Housing

#### Non-Governmental:

- Founding board members, friends and family
- Broad-based community donations (70-80%)
- Foundations, family offices, and corporations (20-30%)
- Equity financing
- Debt
- Resident family-funded / co-ops
- Home sales:
  - Families for their children (Family Opportunity Mortgage)
  - Benevolent investors

#### Governmental:

- Tax credits
  - LIHTC Low-Income Housing Tax Credits (4% and 9%)
  - NMTC - New Markets Tax Credits
- HOME Investment Partnership Program
- Housing and Mortgage Finance Agency (NJ)
- Affordable Housing Trust Funds
- Land Banks
- Other state-specific funds
- Legislative appropriations

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### Case Study: Riverflow Community



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### Case Study: Riverflow Community



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### Case Study: Riverflow Community



[www.riverflowcommunity.org](http://www.riverflowcommunity.org)

#### Background

- 90%+ currently Shared Living Providers
- Least expensive - IRC 131
- i.e., Adult Foster Care - typically no long term stability, particularly for high support needs individuals
- Parents organize & advocate for change
- Legislature listens
- Vermont Act 186 (June 2022) - Planning Grants for Alternative Models

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## Case Study: Riverflow Community



[www.riverflowcommunity.org](http://www.riverflowcommunity.org)

### Enter Riverflow! - Summer & Fall 2023

- Families and Intentional Living Professional form Riverflow
- Awarded Vermont one of the Act 186 Grants
- A marathon... but also a sprint
- Building the plane while flying...
  - Building the Team
  - Fundraising
  - Gov't approvals - IRS, Local Zoning, State Licensing (under CMS HCBS framework)
  - Renovations

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## Case Study: Riverflow Community



[www.riverflowcommunity.org](http://www.riverflowcommunity.org)

### Two Biggies

- Funds for Bricks & Mortar
  - Founders
  - Friends & Families
  - Foundations
  - Grants
- Sustainable Operational Budget
  - IRC 119

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## Case Study: Riverflow Community

January 2024 - start here... 🤖 🤖



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## Case Study: Riverflow Community

October 2024 - End here! 📢 📢 📢



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## How To Find Housing Options



**Autism Housing Network** - [www.autismhousingnetwork.org](http://www.autismhousingnetwork.org)



**Together for Choice** - [www.togetherforchoice.org/housing-directory](http://www.togetherforchoice.org/housing-directory)



**Special Needs Alliance** - [www.specialneedsalliance.org](http://www.specialneedsalliance.org)



**State Medicaid Agencies** - generally lists of group homes and institutions (if any) in each state, provider or government-controlled



**Google** - local, state, and national options



**Word of Mouth / Advocacy Groups / Social media** - local options

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## Survey of Interest in Continuing Education Webinar Series

50-minute session covers only a fraction of the subject matter for housing for adults with IDD.

The QR code opens a 4-question survey to gauge the interest in an informational or continuing education webinar series that informs about housing in greater detail.

Link: <https://s.surveypal.com/uz789er8>



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# Q&A

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