

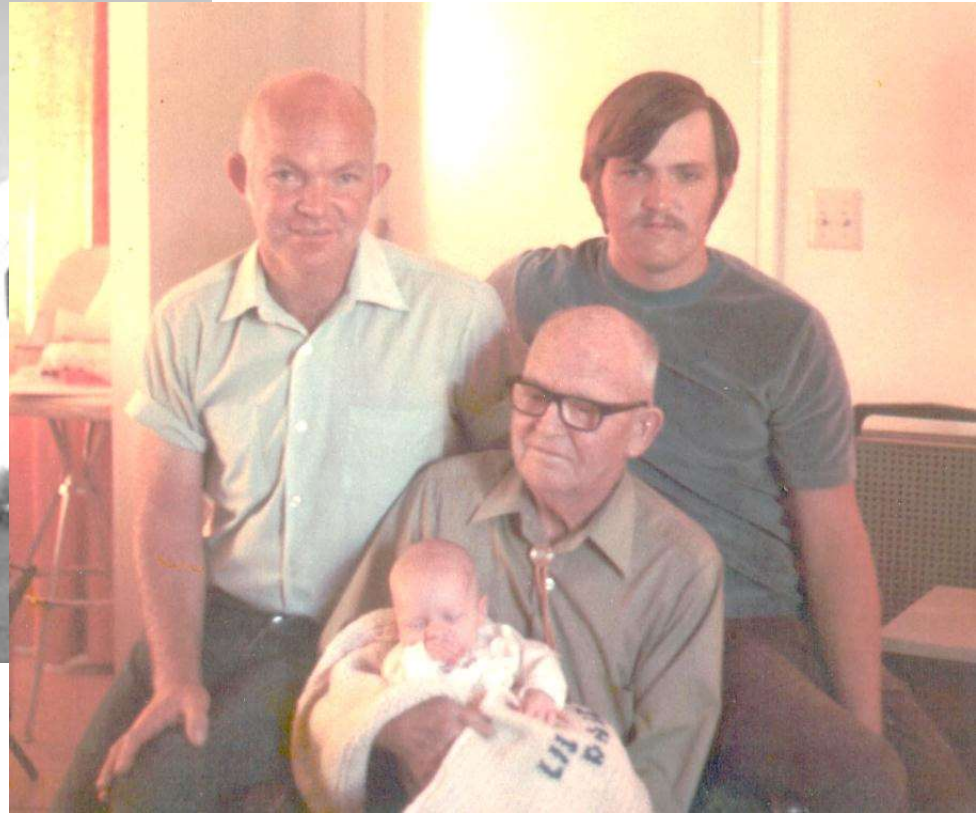


# The Life Passage Planning Project

A Project of the Center for Excellence in Elder Law

Preface  
My Story Begins

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# The Life Passages Project -

- A nationally recognized Team of Experts in Pooled Special Needs Trusts will:
  - Create and implement a **new standard of Best Practices** and aggressively train, educate and seek active implementation by Pooled Special Needs Trusts and trustees across the country – creating a new standard of excellence
  - Create and implement a new **person centered tool for assessing the needs** of the beneficiary and what will ensure a quality life
  - Create and implement a new model for **Life Passage Support** through Pooled Special Needs Trusts that engages local staff of community agencies with beneficiaries in a more person centered and cost effective way – all leading toward
  - Create and distribute a **new consumer and professional education campaign** aimed at parents and other family member to help people understand the importance of planning and ensure they do not leave money in the wrong way impacting benefits of beneficiaries

# Guiding Principles for the Life Passage Planning Project

- **To adapt and improve existing systems**, concepts and resources in a way that better serves beneficiaries of special needs trusts.
- Life Passage Planning system will **develop and implement a system of assessment and delivery of services** to beneficiaries of special needs trusts that coordinates the efforts of all stakeholders in providing quality of life to beneficiaries of special needs trusts.
- **The Life Passage Planning system will work with participating programs that provide direct services to persons with disabilities that can easily adapt to the system to deliver services to beneficiaries at a higher quality, and lower cost, while providing the agencies a sustainable stream of income higher than the rates they currently receive from government funded programs.**

# What is Life Passage Planning?

- Life is a journey, a passage. We have chosen the title Life Passage Planning, helping individual beneficiaries with their passage.
- This is based on a maritime concept used by sailors for centuries called Passage Planning.
- Passage planning consists of four stages:
  - appraisal,
  - planning,
  - execution, and
  - monitoring.[\[2\]](#)
- We believe this process will serve beneficiaries well, provide guidance to families and support the efforts of the PSNT community.

# What is Passage Planning?

- You can't take a ship from Nantucket to Zanzibar without a plan.
- A voyage of this sort needs the coordination of many people and entities to safely get to the destination.
- Providing for the quality of life of a person with a disability requires similar coordination of efforts.

## About the Center for Excellence

- Stetson University, founded in 1883, is a private university located in Deland Florida. The College of Law is one of four colleges and schools of Stetson University. The College of Law, located in Gulfport, Florida, is Florida's oldest law school. The Center for Excellence in Elder Law (hereafter Center) is one of four Centers at the College of Law, with a mission that focuses on meeting the increasing need for legal education and research in the field of law and aging. The Center provides legal education to law students, attorneys, and judges in the field of elder and special needs law and produces scholarly research and writing on issues impacting those who are older and/or have special needs.
- As well, the Center is known for its work in special needs trusts. The Center for Excellence hosts an annual three day conference on special needs planning. The first day includes a pre-conference for those involved with pooled special needs trusts. The two days following, referred to as the national conference, includes general sessions of interest to everyone, regardless of experience level and the afternoons include breakout sessions with three tracks: basics, advanced and administrative. Professor Morgan has served as the conference chair for this conference since its inception. Always held the third Thursday-Friday of October, this year marks the 19th year of the conference. In addition to this in-person conference, every spring the Center, through Professor Morgan, hosts a half-day webinar devoted to fundamentals of special needs trust administration. Professor Morgan is also the co-author of the book Fundamentals of Special Needs Trusts (published by LexisNexis) and co-author of Planning for disability, part of the BNA Tax Portfolio Series. Professor Morgan and her co-author are in the process of updating Third Party & Self-Created Trusts, published by the American Bar Association.



# John Dickerson

- John Dickerson began his career with The Arc in 1973 after graduating from Huron College, Huron, SD. His first task working for The Arc was being part of a statewide effort developing the plan for a free public education for all children with disabilities, something unavailable at that time. His career started with The Arc of South Dakota, moved to the assistant director of The Arc of Indiana, then to The Arc of the US and he returned to The Arc of Indiana as executive director from 1983-2015.
- Key milestones in his career were the transformation of services in Indiana – the closure of all state hospitals by creating community supports for the people who lived in five state institutions; lowering the waiting list from 12 years to 1 year.
- John led the development of The Arc Trust, one of the oldest and largest PSNT in the country. Over 4,000 families and individuals have enrolled, assets managed exceed \$65 million and distributions this year will be between \$5 - \$6 million dollars for beneficiaries. All done with a staff of 9 people – and The Arc Trust is completely self-sustaining in its 28th year.
- John also led the development with his team of The Arc owning and operating a 150 room Courtyard by Marriott which has the country's first every training institute embedded in the hotel – training people with I/DD the hospitality industry while they live, work and learn in the hotel for 9 weeks.
- John left the Arc is now the founder and CEO of Quillo , a unique new approach to the workforce crisis facing organizations serving people with disabilities. The new app will launch this fall and is designed around the concept of inspiring, engaging and educating our workforce while focusing on their personal well being.

Stephen W. Dale  
Attorney,  
disability rights  
advocate and  
trustee of the  
Golden State  
Pooled Trust

- Stephen W. Dale is an attorney and trustee of the Golden State Pooled Trust which will be a key participant in this project. The Golden State Pooled Trust is a program under the North Bay Housing Coalition (NBHC) which is a nonprofit that focuses on the housing for persons with developmental disabilities in Solano, Napa, and Sonoma counties.
- The Golden State Pooled Trust was established by the board of the NBHC in part to be a model of advocacy for all persons with disabilities, with the goal of setting a higher standard in the special needs trust industry. The board of the NBHC felt that there are too many PSNTs that focus on using their trusts as a fund-raising mechanism, and do not fully inform potential beneficiaries of all their options. To remedy this, the Golden State Pooled Trust requires all potential beneficiaries to be counseled by an independent attorney to ensure that potential beneficiaries are counseled on all their options prior to joining the trust.
- The Golden State Pooled Trust maintains accreditation as a provider for continuing education by the California State Bar, and provides education on a variety of different topics. In addition to education on benefits, the Golden State Pooled Trust also does education for referring attorneys as well as beneficiaries and their advocates on a wide variety of subjects, including a series of YouTube videos called “Essentials of Disability Advocacy” which are subjects that the board of the Golden State Pooled Trust believe that attorneys and professionals who serve persons with disabilities should understand to better serve their clients and communities. In an attachment entitled “Golden State Pooled Trust Video Links” there are links to the different playlists of many of the videos that are available to both professionals and the public.
- The board of the NBHC was also concerned that many PSNTs require that the remainder interest be left to the trust, causing an immediate conflict of interest. The board has directed that no beneficiary shall be required to leave their remainder to the Golden State Pooled Trust to avoid even the appearance of a conflict.
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What is the  
need or  
challenge  
being  
addressed by  
the proposed  
project?

- With Special Needs Trusts (SNTs) in existence for over 3 decades, the need for families to be able to set aside funds for their loved ones with disabilities has increased due to declining government funding of the community programs that provide supports to assist many persons with disabilities to meet their basic needs.
- Pooled Special Needs Trusts (PSNTs) are particularly important for families of modest means who do not have the resources to leave an amount of assets high enough to be managed by corporate trustees.
- For example, the Wells Fargo Trust Department has a requirement of a minimum of \$1 million which limits their services to most families with disabled loved ones.

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- **Very few PSNTs have staff to provide these services and must often contract with private professional care managers who typically charge a higher rate somewhere between \$100-\$150 an hour.**
- It is envisioned that PSNT's could pay the DSP agency twice that amount for many of the services only available by private care managers, resulting in the DSP agency being more stable, and raising the pay rates of the DSP worker, reducing staff overturn and increasing agency stability by not being totally dependent on rates funded by Medicaid.
- By using DSP agencies such as Supported Living Services (SLS) agencies in California that utilize the proposed education, training, and materials that will be developed through the proposed project, PSNTs will have access to staff trained specifically to meet the needs of their beneficiaries at a fraction of the cost of a professional care manager and more effectively.

How Will the Life  
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- One outcome would be to create a person-centered system that serves the beneficiary and gets a non-governmental stream of income to the agencies resulting in
  - greater stability of the agencies,
  - workers of the agency receiving a higher salary and benefits resulting in less turnover, and
  - the PSNT will be able to provide more services and oversight to their beneficiaries at an affordable cost.

## How Will the Life Passage Planning Project Meet this Challenge?

- **Standardized Needs Assessment Process**
- This project will develop a more person-centered, cost- and operationally-effective, locally based needs assessment process to ensure that the PSNTs have the resources to provide assessment of the beneficiaries needs and wrap around services. To be effective family members need to be clear on needs and service expectations based on available financial and local service provider services.
- The Life Passage Planning team will develop materials specifically defining the benefit that a comprehensive system can have on ensuring their loved one's quality of life, and educate families on how the process works.
- It is anticipated the education for persons with disabilities and families will be housed on websites of disability organizations including the Center for Future Planning.

Who will benefit from the proposed activities?

- We expect that the benefits from this project will be profound.
- **PSNTs, Corporate and Private Fiduciaries** - While the project will focus primarily PSNTs, the guidelines, tools and education that will be developed will be of value to all SNT trustees including corporate and private fiduciaries.



## Who will benefit from the proposed activities?

- **Beneficiaries of SNTs** - By creating a standardized system of assessment and delivery of services, trustees will have the ability to increase their capability to better serve their beneficiaries by creating access services currently not available to many beneficiaries. **For instance, beneficiaries with a mental health diagnosis cannot access many of the services the SLS agencies provide to persons with I/DD.**
- This project will allow the PSNT to purchase those services, broadening their ability to serve their beneficiaries. With the proper systems and education in place, the DSP provider will be able to better document expenditures in a manner that will be compliant with the rules imposed by the Social Security Administration and Medicaid agencies reducing the incidents of loss of benefits.

Who will  
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- **Courts** - Many of the cases held by PSNTs are from civil cases including birth injury settlements or misdirected inheritances. In many states these cases remain under court supervision but because there is no standardization of recording needs and disbursements a great deal of court time is wasted by judges and court staff when reviewing the accountings of these accounts causing increased cost to the beneficiaries account and the taxpayer.

Who will benefit from the proposed activities?

- **DSP Agencies and Staff** - DSP agencies will be able to expand their client base at a rate significantly higher than typically received from government funded rates. This project will not only increase the revenue for the DSP provider, it will give them a non-governmental stream of income.

Population(s)  
targeted and  
identifying  
participants.

- The project is designed to be developed, validated and executed in phases.
- The initial phases will begin in California focusing on California's SLS agencies that serve persons with I/DD.
- SLS agencies will be selected based on their location and ability to adapt their existing systems and processes.

Population(s)  
targeted and  
identifying  
participants.

- In the 2nd year the Center and expert team will work with other PSNTs both in California and other states selected based once on many factors including the availability of DSP agencies that can easily adapt to the projects system as well as number of potential beneficiaries they might serve.

## Bringing the Service System for Persons with I/DD and Expand it to Cross Disabilities

- This will bring services to from the Lanterman system to all persons with disabilities.
- Eventually create a network that is available to all trustees of special needs trusts across the country by creating a network of agencies that serve all persons with disabilities
- Create a standardized system of assessment and delegation of duties based on a person centered system
- Be adaptable to the unique needs of persons with disabilities and increase options. Example – PLAN of Vancouver and quest for sustainable micro-board options to work in the US.

## What Can You Do?

- **Direct Service Provider Agencies**
- **Persons with disabilities and families**
- **Trustees and advisors on special needs trusts**
- **Financial and tax advisors**
- **This is not for everyone, and is not intended to replace natural or agency supports**
- **It will provide a new level of service for many, and a safety net for others.**
- **The program has an open architecture which allows adaptation**

To Learn More  
and  
Participate

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To learn more or  
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- Fair Winds  
and  
Following  
Seas to All