2026 National Conference on Special Needs Planning and Special Needs Trusts

STETSON UNIVERSITY

October 21-23, 2026

My Cloudy Crystal Ball:

Planning for Special Needs Beneficiaries Throughout Their Lifetime in an Era of Change

Stephen W. Dale, JD, LLM
The Dale Law Firm
Golden State Pooled Trust
www.dalelawfirm.com
steve@dalelawfirm.com

Peter J Wall
Director, Fiduciary Services
True Link Financial Advisors, LLC
www.truelinkfinancial.com
peter.wall@truelinkfinancial.com

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I. Introduction

The enactment of the “One Big Beautiful Bill Act” (HR 1) has renewed concern among families, advocates, and professionals engaged in long-term planning for individuals with disabilities. In particular, it has raised questions about the durability of public benefits, the stability of service delivery systems, and the continued viability of estate plans and special needs trusts (SNTs) built on assumptions that may not hold over a beneficiary’s lifetime. The central planning challenge, therefore, is whether the plan has been designed as a system capable of making ongoing incremental adjustments while also withstanding the inevitable shifts in public policy, funding, and administration that occur over a beneficiary’s lifetime.

Imagine that today we are planning for Kathy, a seventeen-year-old woman with a significant developmental disability. Kathy is physically healthy, but she is likely to need some degree of supervision, decision-making support, advocacy, and coordinated services throughout her life. Her parents do careful planning and establish a fully funded third-party SNT to enhance her quality of life while preserving access to public benefits when appropriate.

Then imagine that, shortly after the plan is completed, Kathy's parents pass away. The trust becomes irrevocable and enters active administration. The trustee may now be administering a system for most of Kathy's adult life. The Social Security Administration's 2023 period life table, used in the 2026 Trustees Report, gives a seventeen-year-old female an average remaining life expectancy of approximately sixty-

four years.[1] The number is not a prediction of Kathy's life; it is a planning warning. A trust that begins administration when a beneficiary is young may still be operating in the 2080s or 2090s.

Over that horizon, virtually every assumption made at the drafting table will change. Public benefits will change. Service systems will expand and contract. Housing models, health care, technology, trustees, advisors, providers, and family involvement will change. Kathy's own preferences, abilities, relationships, and support needs will also evolve.

The important point is not that the future will necessarily be worse. It may be better in ways we cannot yet imagine. Assistive technology, communication tools, transportation, housing models, medical advances, self-direction, and employment opportunities may increase independence. Flexibility is needed not only to survive disruption, but also to capture opportunity.

> ***The goal is not to predict the future. The goal is to build a plan that can adapt when our predictions are wrong.***

While HR 1 offers a contemporary illustration of this dynamic, it is not the thesis of this paper. Public policy changes repeatedly. By examining these patterns, planners can better anticipate the types of disruptions SNT beneficiaries are likely to face. The

[1] Social Security Administration, Actuarial Life Table, Period Life Table 2023, as used in the 2026 Trustees Report, https://www.ssa.gov/OACT/STATS/table4c6.html (female age 17: 63.84 years remaining life expectancy).

durable question is whether the plan has enough discretion, governance, information, advocacy, and periodic review to respond when the surrounding system changes.

One key point to remember is that every person with a disability is a unique individual. Kathy's example isn't meant to imply that all planning scenarios are the same, or even similar. Instead, special needs planning should always be customized to fit each individual, considering factors like diagnosis, family dynamics, resources, and personal goals—all of which can vary widely. Kathy's story highlights an important idea - when planning needs to span an entire lifetime, it's crucial that the plan is flexible enough to accommodate change. Flexibility, clear processes, and good governance aren't just nice-to-haves—they are vital for effective special needs trust planning.

II. Defining the Planning Horizon

Before examining why planning must anticipate change, planners should define the period and purpose for which the plan is intended to operate. Too often, the unspoken administration strategy is simply to spend the trust until it runs out. A better approach begins by identifying the trust's intended role in the beneficiary's life and aligning drafting, funding, governance, and administration with that purpose.

Kathy may require supervision, decision-making support, and coordinated services throughout her life. Because she is physically healthy, her trust may need to function for sixty years or more. Other beneficiaries may have much shorter planning horizons or a period of intensive support followed by greater independence. The point is not to force every plan into a lifetime model. Rather, it is to make the intended trajectory explicit.

A trust may be designed to fund education, vocational training, supported employment, housing, or a defined transition toward greater independence. Where family resources are limited, it may be appropriate to spend strategically on services that increase self-reliance and long-term stability rather than attempt to replace a lifetime of public or family support.

The fundamental planning error is failing to define the trust's intended trajectory: its objectives, its role in the beneficiary's life, and the degree to which it must adapt over time. Attorneys and advisors should clarify not only how long the plan may operate, but what the plan is supposed to accomplish.

III. Planning Must Assume Change

Once the design direction is established, the next step is recognizing that change is not an exception to be managed but a constant to be anticipated. Planning that assumes stability in laws, services, or family involvement may work in the short term but is fragile when assessed over the lifetime of a person with a disability.

For a beneficiary like Kathy, change will occur across several dimensions at once. Public-benefit rules may be amended, reinterpreted, or administratively revised. Service systems may expand or contract in response to funding priorities and workforce challenges. Medical advances and aging may alter functional capacity and support needs. The informal advocacy network that initially supports the beneficiary will change as parents and family members age, relocate, or pass away.

The plan therefore needs process, not prophecy. Fiduciaries should be able to assess circumstances as they exist at a given time, document their reasoning, adjust distributions and services, and remain anchored to the beneficiary's goals even when the tools available to achieve those goals are different from those anticipated at the drafting table.

IV. Looking Back: Seventy Years of Disability Policy

If Kathy may live another sixty or seventy years, one way to think about the changes she may encounter is to look back over the last sixty or seventy years. The history of disability services shows just how much can change within a single lifetime: institutions can rise and fall, federal priorities can shift, community systems can expand or contract, and new rights and service models can emerge. History cannot predict the future, but it can help us understand the kinds of change a long-term plan must be prepared to absorb.

A. Institutional Origins and Early Reform

In the nineteenth and early twentieth centuries, reformers advocated for public institutions as alternatives to jails, poorhouses, and almshouses for people with mental illness and developmental disabilities. Many institutions were created with sincere aspirations of safety, schooling, medical supervision, structure, work, recreation, and protection. Yet those systems depended on sustained funding, adequate staffing, manageable populations, and meaningful oversight.

As admissions increased and resources failed to keep pace, many institutions became overcrowded and understaffed. Therapeutic aspirations gave way to

custodial care. Burton Blatt and Fred Kaplan's 1966 photographic essay, Christmas in Purgatory, became one of the most influential depictions of institutional conditions during this era. [2][2] The planning lesson is not that reformers lacked compassion. It is that a service model can begin with humane intentions and still deteriorate when its operating conditions change.

B. Deinstitutionalization and Federal Expansion

By the middle of the twentieth century, investigative reporting, litigation, family advocacy, disability-rights organizing, and broader civil-rights movements prompted a reassessment of institutional care. The federal legislation commonly associated with the Community Mental Health Act of 1963 authorized grants for community mental-health centers, while the Mental Health Systems Act of 1980 later sought a broader federal role in planning and supporting community mental-health services.[3,4]

The aspiration was that people should not be unnecessarily confined and that meaningful supports should exist in the community. But community-based systems required persistent funding, workforce development, administrative capacity, housing, crisis services, and political support. Closing an institution can be measured. Building a durable community infrastructure over decades is harder.

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[2] Burton Blatt & Fred Kaplan, Christmas in Purgatory: A Photographic Essay on Mental Retardation (1966).

[3] Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963, Pub. L. No. 88-164, 77 Stat. 282 (1963), including Title II concerning community mental health centers.

[4] Mental Health Systems Act, Pub. L. No. 96-398, 94 Stat. 1564 (1980).

C. The 1981 Retrenchment

The Omnibus Budget Reconciliation Act of 1981 marked an important turn in federal mental-health policy. It repealed major portions of the Mental Health Systems Act and shifted funding toward block grants and greater state discretion.[5] It did not affect every disability program in the same way, and it should not be treated as a single explanation for the later condition of community services. It nevertheless illustrates a recurring planning reality: financing structures and governmental responsibility can change even while the underlying need for services remains or grows.

For special needs planners, the historical point is straightforward. A benefit or service structure that appears established today cannot be assumed to operate in the same form decades from now. State choices, waiver design, appropriations, provider markets, and administrative capacity can materially affect what an eligible person actually receives.

The comparison to current federal policy is not that H.R. 1 repeats OBRA 1981 or converts Medicaid into a block-grant program. Rather, OBRA 1981 illustrates how changes in federal financing and federal-state responsibility can reshape service systems over time, often in ways that are difficult to foresee when legislation is enacted. That historical lesson provides useful context for evaluating H.R. 1 and other future policy changes over a beneficiary's lifetime.

[5] Omnibus Budget Reconciliation Act of 1981, Pub. L. No. 97-35, 95 Stat. 357 (1981).

D. A Mature System Can Still Change: California Mental Health

In California, the Short-Doyle Act of 1957 supported locally administered community mental-health programs years before the later federal initiatives. Over time, state financing formulas, deinstitutionalization, Medi-Cal, and fiscal realignment repeatedly changed how the system was organized and funded.[6]

Here, it is clear that even a mature community system can retain important strengths while its financing, administration, local capacity, and service mix continue to evolve. For a long-term planner, the relevant question is not whether a program survives in name. It is whether the beneficiary can obtain the needed support when the need arises.

V. Community Living

Community systems can fail in different ways: too few waiver slots; inadequate crisis services or supported housing; weak transition planning; insufficient workforce capacity; poor quality oversight after a service is authorized; fragmented state and local administration; or long delays between eligibility and actual service delivery.

A. Texas: Interest Lists and Capacity-Limited Supports

Texas programs illustrate the planning risks created by capacity-limited systems. Texas maintains interest lists for multiple long-term services and supports waiver programs, including Home and Community-based Services and Texas Home

[6] California Legislative Analyst's Office, Major Milestones: 43 Years of Care and Treatment of the Mentally Ill (2000), https://lao.ca.gov/2000/030200_mental_illness/030200_mental_illness.pdf.

Living.[7] Placement on an interest list is not the same as enrollment, and services depend on program rules, available capacity, and an eventual offer.

Texas also continues to operate State Supported Living Centers. In 2009, the U.S. Department of Justice and Texas entered into a settlement addressing conditions and practices at thirteen state facilities, including protection from harm, behavioral and mental-health services, health care, discharge planning, and support for integrated placement.[8] While these efforts produced measurable operational improvements, they did not alter the underlying structural reality: Texas' system continues to depend heavily on discretionary funding, constrained program capacity, and administratively complex service delivery.The example shows that a state may simultaneously maintain institutional capacity and community programs while still confronting substantial questions of access, quality, and transition.

B. Different States, Different Failure Modes

Virginia demonstrates another pattern. A 2012 federal settlement was designed both to expand community services for people with intellectual and developmental disabilities leaving institutions and to reduce the risk of unnecessary institutionalization for people living in the community, including people waiting for waiver services. The agreement required thousands of new home- and community-

[7] Texas Health and Human Services, Community Services Interest List, Revision 26-2 (effective June 1, 2026), https://fhb.hhs.texas.gov/handbooks/star-kids-program-support-unit-operational-procedures-handbook/1500-psu-online-database-resources.

[8] U.S. Department of Justice, Justice Department Files Complaint and Reaches Settlement to Improve Conditions at Texas State Facilities for Persons with Developmental Disabilities (June 26, 2009), https://www.justice.gov/archives/opa/pr/justice-department-files-complaint-and-reaches-settlement-improve-conditions-texas-state.

based waiver opportunities, family supports, crisis services, housing assistance, supported employment, and quality oversight.[9]

New Hampshire's mental-health settlement illustrates a different set of gaps: statewide Assertive Community Treatment, supported housing, mobile crisis services, and other community supports were central to the remedy.[10] These examples do not prove that community living is unrealistic or that every state system is failing. They demonstrate that community living depends on durable capacity, and the weak point differs by jurisdiction. Additionally, most state programs' demand has consistently exceeded available waiver slots, resulting in wait times that often extend for many years. For families, placement on a waiting list offers limited predictability regarding when, if ever, meaningful support will become available.

As such, for trustees and planners, geography may be a planning variable. A trust created in one state may later be administered for a beneficiary living in another. Eligibility does not always mean timely service availability. A move may alter waiver access, provider networks, housing opportunities, transportation, state supplementation, care-management options, and the beneficiary's informal support network.

When service systems are contingent rather than guaranteed, families cannot assume continuity, adequacy, or timeliness of public support. Effective special needs planning must therefore account not only for eligibility rules, but also for service

[9] U.S. Department of Justice, United States v. Commonwealth of Virginia, Settlement Agreement and Fact Sheet (2012), https://www.justice.gov/crt/united-states-v-commonwealth-virginia.
[10] U.S. Department of Justice, New Hampshire ADA Mental Health Settlement Fact Sheet, https://www.justice.gov/crt/about/spl/documents/nhada_factsheet.pdf.

delays, workforce instability, geographic disparities, and the likelihood that private resources may be required to bridge gaps for extended periods. These issues underscore why SNTs must be capable of supplementing—and, when necessary, temporarily replacing—public services in order to preserve a beneficiary's quality of life over time.

VI. H.R. 1 in Historical Context

H.R. 1 should be understood as a contemporary illustration of system change, not as an unprecedented event or a prediction that every person with a disability will lose benefits. The law does not eliminate Medicaid, and important exclusions apply to many people with disabilities and caregivers. For beneficiaries with intellectual, developmental, or psychiatric disabilities, the primary risk posed by H.R. 1 is often not substantive ineligibility but procedural failure. Increased reporting obligations, shortened eligibility windows, and heightened verification requirements disproportionately affect individuals who rely on representative payees, family members, or service providers to navigate complex administrative processes. Even temporary lapses in compliance can result in benefit suspension, service disruption, or the loss of provider relationships.

CMS's June 2026 interim final rule explains that the new Medicaid community-engagement requirement generally applies to specified non-pregnant adults ages nineteen through sixty-four who are eligible for the Medicaid adult group or certain comparable demonstration coverage, and the rule recognizes statutory exclusions and

exceptions.[11] It would therefore be inaccurate to assume that the requirement applies to every Medicaid beneficiary with a disability.

The larger planning lesson is administrative. Changes in eligibility procedures, reporting, renewal, financing, or coverage rules can create friction even when the core program continues. New forms, deadlines, verification systems, agency guidance, and state implementation choices can produce delay and uncertainty. In a capacity-limited system, administrative disruption can compound an existing service gap.

The professional response should not be fear-based drafting around one statute. It should be a governance structure that can recognize a change, obtain current advice, reassess available public and private supports, and authorize an appropriate response. The objective is not to predict the next policy shift but to ensure that the plan remains functional and responsive when it occurs.

VII. Why Static Special Needs Planning Is Fragile

Much special-needs planning remains implicitly static. Trusts may be drafted with careful attention to current eligibility rules and technical compliance but sometimes pay insufficient attention to how those provisions will function when circumstances inevitably change.

Static planning overvalues present-day benefit structures. It also underestimates human turnover. Trustees, advisors, care providers, and family advocates will change. Without

[11] Centers for Medicare & Medicaid Services, Medicaid Community Engagement Requirement for Certain Individuals Interim Final Rule with Comment Period (CMS-2454-IFC), Fact Sheet (June 1, 2026), https://www.cms.gov/newsroom/fact-sheets/medicaid-community-engagement-requirement-certain-individuals-interim-final-rule-comment-period-cms.

mechanisms to preserve institutional knowledge, guide successor fiduciaries, and recalibrate decision-making, administration can become reactive rather than intentional.

Static design also underestimates cumulative change. A modest service reduction, a new administrative requirement, a housing problem, a provider closure, or a temporary gap may each appear manageable in isolation. Across decades, small changes compound. Drafting that was technically elegant at inception can become poorly matched to the beneficiary's actual life.

> ***A long-term plan should be designed to remain useful after the assumptions that produced it are no longer true.***

VIII. Designing an Adaptive System

Although these principles inform many forms of special-needs planning, the examples here primarily assume a third-party SNT. First-party trusts, pooled trusts, and settlement-funded trusts can involve additional statutory, reimbursement, tax, and fiduciary considerations.

The solution is not merely broader drafting language. The trust instrument is indispensable, but it is only one component of the plan. The operative plan is a system of people, information, governance, advocacy, financial resources, monitoring, and reassessment. For beneficiaries whose needs may extend across decades, a trust should provide a framework for ongoing decision-making rather than a fixed set of instructions tied to present conditions.

At the core of this approach is recognition that no drafting attorney, trustee, or family can accurately predict the beneficiary’s future needs, the availability of public services,

or the legal and administrative environment in which the trust will operate. Effective design therefore emphasizes process over prediction. The trust must empower fiduciaries to assess circumstances as they exist at any given point in time and to respond deliberately as those circumstances change.

A. Why Institutional Continuity Matters: The Pooled Special Needs Trust Example

Pooled Special Needs Trusts ("PSNTs") illustrate one way to build continuity into long-term administration. Federal law permits a qualifying PSNT to maintain separate beneficiary accounts while pooling funds for investment and management purposes, with the trust established and managed by a nonprofit association.[12] That structure can provide continuity beyond any one parent, sibling, trustee, advisor, or service provider.

A pooled trust does not eliminate uncertainty, and pooled trusts are not interchangeable. The master trust, joinder agreement, distribution policy, investment policy, administrative systems, and applicable state Medicaid rules all matter. Institutional continuity can reduce the risk that a beneficiary is left without knowledgeable administration when family advocates are no longer available.

B. Process-Based Administration and an Annual Distribution Plan

A practical way to implement flexibility is a recurring planning process, often embodied in an annual distribution plan. Rather than treating distributions as a

[12] 42 U.S.C. § 1396p(d)(4)(C); see also Social Security Administration, POMS SI 01120.203 (pooled trust requirements).

series of ad hoc approvals, the annual plan identifies anticipated needs, evaluates available public benefits and services, establishes priorities for trust expenditures, and documents the reasoning behind major tradeoffs.

For Kathy, the process should incorporate input from the trustee, legal and financial advisors, care managers, and, to the greatest extent practicable, Kathy herself. The objective is not merely to budget funds. It is to create a shared picture of goals, risks, resources, and responsibilities and to revisit that picture as circumstances change.

C. Governance, Oversight, and Continuity

Flexibility must be paired with accountability. Over a long planning horizon, trustee turnover is inevitable and institutional knowledge can be lost. Governance structures such as advisory committees, trust protectors, designated successor fiduciaries, and documented decision-making protocols can preserve intent and provide checks and balances.

The drafting question is not simply who should serve today. It is how the system will select, monitor, replace, and educate the people who will serve later.

D. Funding, Sustainability, and Tradeoffs

Adaptability requires an honest assessment of funding. Trustees must balance current quality-of-life expenditures with the need to preserve resources for later stages of life, including periods of increased health, housing, or support needs. Inflation and rising labor and housing costs make the analysis more difficult.

Where resources are limited, the plan may need to prioritize expenditures that increase long-term independence or prevent larger future costs. A technically correct

distribution plan is not enough; fiduciaries need a method for deciding among competing good uses of a finite fund.

E. Flexibility With Public Benefits

Public benefits are tools, not the ultimate objective. A trust designed for adaptability should be able to supplement—and, when appropriate and legally permissible, temporarily replace—public services when delay, disruption, or administrative failure would otherwise jeopardize the beneficiary's safety, housing, dignity, autonomy, or quality of life. Preserving eligibility can be important, but eligibility should not become an end in itself.

IX. Advocacy

Parents often become highly skilled advocates through years of interactions with schools, service providers, medical systems, and benefit agencies. They learn the beneficiary's history, communication style, warning signs, preferences, tolerances, relationships, and the practical difference between a service that is authorized on paper and a service that actually works.

When a parent dies or can no longer serve, the assets may transfer neatly into a trust. The advocacy does not. That function must be intentionally transferred through people, records, relationships, governance, and recurring review.

A trustee should have a process for recognizing when the beneficiary's informal advocacy network has weakened. At that point, the plan may need to fund care management, independent monitoring, advocacy support, supported decision-making

assistance, or other protective services. The annual distribution plan is a natural place to ask whether the beneficiary's living situation, providers, health, relationships, safety, and goals still align with the plan.

By embedding advocacy and oversight in the trust's ongoing process, planners can reduce the risk that a beneficiary becomes isolated or underserved as family involvement diminishes over time. This approach reflects a realistic understanding of long-term administration: safeguarding quality of life over an actuarial lifespan requires vigilance, coordination, and a structure that treats advocacy as a core trust function rather than an optional add-on. A practical solution to addressing advocacy may look like the following:

Practical Planning Matrix

Planning issue	Adaptive design response team
Change in public benefits or services	Trustee or pooled-trust administrator discretion to supplement or temporarily replace supports; periodic reassessment of available benefits and services.
Parent or sibling can no longer advocate	Care-manager role, advisory committee, designated advocates, and documented beneficiary preferences, history, and communication needs.
Trustee turnover or administrator succession	Successor-fiduciary process, organized records, written annual plans, and a governance mechanism capable of replacing a poorly performing fiduciary.
Service or provider failure	Authority to change providers, fund interim supports, and obtain independent assessment or care management.
Change in beneficiary needs or preferences	Recurring review that includes the beneficiary to the greatest extent practicable and revisits goals rather than merely prior spending patterns.
Geographic move	Reassess state-specific benefit rules, waiver or interest-list access, providers, housing, and the local support network.
Funding pressure	Multi-year cash-flow review, reserves where appropriate, and an explicit process for prioritizing quality-of-life expenditures.

Of note, this Practical Planning Martix is intentionally process-focused. It does not attempt to predict which benefit program, provider, or family member will be present in a particular year. It identifies recurring categories of change and pairs them with a structure capable of responding.

Taken together, these design principles reflect a fundamental shift in perspective: when planning for the actuarial life of a beneficiary, flexibility and governance are not optional features but essential components of competent SNT planning.

X. Ethical and Professional Considerations

Periods of policy volatility heighten the professional demands on attorneys, trustees, and advisors. Competent representation requires more than technical compliance with current law; it also requires careful counseling about long-term risk, tradeoffs, and the limits of predictability. The ABA Model Rules frame competence in terms of legal knowledge, skill, thoroughness, and preparation, and require lawyers to explain matters sufficiently for clients to make informed decisions.[13]

One ethical challenge is fear-based planning. Legislative change and media coverage can create pressure to draft around the latest perceived threat or to promise certainty where none exists. Overreaction can be as harmful as complacency when it produces rigid provisions that constrain future fiduciaries.

[13] ABA Model Rules of Professional Conduct, Rules 1.1 (Competence) and 1.4 (Communication), https://www.americanbar.org/groups/professional_responsibility/publications/model_rules_of_professional_conduct/.

Families should also understand that preserving eligibility for a public benefit may at times conflict with other objectives, including safety, autonomy, housing stability, or quality of life. Advising a client that private resources may someday need to bridge a service gap is not pessimism. It is part of candid long-term counseling.

Ethical practice also requires humility. No planner can predict future legislation, service systems, technology, family circumstances, or social conditions with precision. The professional answer to uncertainty is not certainty; it is thoughtful design, clear communication, documentation, and a process that can adapt.

XI. Conclusion: Process Over Prediction

Kathy's story illustrates the central challenge of modern special-needs planning. A trust that becomes irrevocable when she is seventeen may operate for six or seven decades. Over that period, public benefits will evolve, service systems will expand and contract, fiduciaries will turn over, technology may create new opportunities, and Kathy's own needs and preferences will change in ways that cannot be fully anticipated at the outset.

The historical record—from institutional care, to deinstitutionalization, to changing federal and state financing, to state-by-state variation in community capacity—shows that instability is not an anomaly. Change is a recurring feature of disability-service systems. But change should not be equated with decline. Future systems may offer supports, technologies, housing models, and forms of independence that are better than anything available today.

For attorneys, trustees, and advisors, the task is therefore not to draft a document optimized only for current conditions. It is to design a system that can function as

conditions change: a trust with sufficient discretion; people who can exercise that discretion intelligently; information that survives family turnover; governance that creates accountability; advocacy that does not disappear with the parents; and a recurring process for reassessing the beneficiary's actual life.

Effective special-needs planning is ultimately measured not by technical compliance at inception, but by whether the plan continues to safeguard dignity, safety, autonomy, relationships, and quality of life decades later. Planning for change is not an exercise in pessimism. It is a recognition of reality—and an opportunity to build a plan resilient enough to benefit from a future we cannot yet see.

The views and opinions expressed in this paper are solely those of the authors and do not necessarily reflect the views of True Link Financial Advisors, LLC.