

PRESENTED AT

18th Annual Changes and Trends Affecting Special Needs Trusts

February 10-11, 2022
Austin, TX

**Quality of Care and Choices for People with
Disabilities**

Ramona Brush

Author Contact Information:
Ramona Brush
arrangeCARE
Austin, TX

Ramonab@arrangeCare.com

Quality of Care and Choices for People with Disabilities

The goal of quality of life considerations is to help make your clients or beneficiaries feel valued and appreciate life despite their challenges. In most cases, distribution requests from beneficiaries to professionals are framed as necessities or needs rather than improving the beneficiary's quality of life. Family members tend to use substitute judgment standards for requesting distributions. Professionals tend to use the best interest standard. This presentation provides dimensions, tools, and specific recommendations of large and small distributions for evaluating distribution requests in part through the quality of life considerations.

A Special Needs Trust serves people with different capabilities throughout their lifespan. Another trust that can be tailored to the beneficiary is the Achieving a Better Life Experience (ABLE) account which is a type of tax-advantaged savings **account** that an eligible individual can use to pay for qualified disability expenses. These trusts can be used to ensure the best possible quality of life for your clients. Today we are talking about beneficiaries who have intellectual, developmental, chronic health and frailty-related issues, behavioral health, or substance abuse issues. Beneficiaries need tailored solutions that balance their need for ongoing care and safety with their need for independence.

Two standards should be considered in person-centered planning: standard of living and quality of life. The standard of living is a sociological tool describing how the beneficiary compares to others. It is measured by more easily quantifiable items, such as life expectancy, employment, income, housing conditions, safety, access to healthcare, and availability of education. The quality of life standard is a much more intangible term than the standard of living, which varies greatly by personal preferences and access to resources. This standard helps ensure that individuals' privacy, confidentiality, and sensitivities are respected. Their interplay is an important component of making distributions. Our focus today will be on how to use the quality of life standard in making distributions.

Maintaining eligibility for public benefits such as Medicaid, conflicts with public policy, laws, rules or regulations, the trust document language itself, size of the trust, or violation of the terms of the trust, allowable disbursements, and beneficiary circumstances are factors making distribution decisions. These elements are beyond the scope of this presentation. This presentation also will not delve into the best interest or substitute judgment standards. Instead, we are going to talk about tools for evaluating distribution requests in part through melding "quality of life" considerations and standards. Finally, I will provide a broad variety of suggestions for "quality of life" distributions.

Here are some principles that you may use as a basis for making quality of life financial decisions:

A core set of unifying quality of life (QOL) principles:

- Well-being within a cultural context
- Well-being within financial constraints
- Changing social ideas about differing abilities

QOL can be divided into seven core domains and indicators based on the 8 Domain Theory, which was posed by Shalock and Verdugo in 1996. This is currently a dominant theory for identifying these domains:

1. Self-determination – choice and making decisions, cognitive ability, a sense of purpose
2. Emotional well-being – positive outlook, hope, depression, loneliness, sexual expression, and other intimacy needs
3. Physical well-being
4. Material well-being
5. Rights
6. Personal development
7. Social inclusion and interpersonal relationship

To determine what is most important to the beneficiary, the trust officer should understand and document the answers to these foundational questions:

1. Are your living conditions within your means and income?
2. Do you feel your living conditions are sustainable, safe, and stable?
3. Do you feel safe in your living area?
4. Do you feel worried about being able to get medical treatment when you need it?
5. Do you feel physically safe when you are at home?
6. Do you have economic safety?
7. Do you have a strong sense of community, feel close to family, and cultivate strong friendships in person and online?
8. Do you have a handful of people you can count on and reach out to when you need help and support?
9. Do you have clear goals and aspirations in life and a strong sense of purpose?
10. How is your health affecting your quality of life?

The following is a tool you can use to quantify your distributions, modified from the San Martin Scale (Verdugo et al 2013)

1. Information about the person being served
2. Information about the informant and relationship

The San Martin Scale includes a key to be used when assessing the priority of your distributions regarding an individual with different capabilities.

N = never
S = sometimes
O = often
A = always

1. Self-determination

Find the full text of this and thousands of other resources from leading experts in dozens of legal practice areas in the [UT Law CLE eLibrary \(utcle.org/elibrary\)](https://utcle.org/elibrary)

Title search: Quality of Care and Choices for People with Disabilities

Also available as part of the eCourse

[2022 Special Needs Trusts eConference](#)

First appeared as part of the conference materials for the
18th Annual Changes and Trends Affecting Special Needs Trusts session
"Quality of Care and Choices for People with Disabilities"