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**Continuity of Care:
People, Process and Documents to Promote
Continuity of Care in Changing Circumstances**

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Continuity of Care:

People, Processes and Documents to Promote Continuity of Care in Changing Circumstances

“Ohana.” Ohana means that nobody gets left behind. But often someone does -- or they land, as it were, on a small island on an unknown planet. Like Stich, they suddenly become a stranger in a strange land, misunderstanding and misunderstood.

How can we help our clients make sure that their loved one does not wash up on some barren, deserted island but instead meets Lilo and becomes part of her family, “broken, but still good”?

Even those of us who ourselves have family members with special needs may sometimes wonder whether they came from outer space. They disrupt our lives. They enrich them. How can we keep them involved? How can we keep them from being left behind?

First, no capes! All too many parents assume that another family member will step up, without considering that family member’s inevitably changing circumstances and needs – or, sometimes, even without discussing the prospective role with that family member. Parents and spouses also tend to underestimate how much is required, how much they do and how hard it would be to replace them. It may not take a village, but it definitely takes a team. Thanks to a grant received by Texas Parent2Parent, we can start creating that team now, letting team members develop connections and processes and documenting what they need to know and do.

Second, practice, practice, practice. A process can always be changed, and probably will be. But starting with the known routine and documenting the details can give the people who help now and the people who take over later a good place to start.

Third, no formulaic special needs trusts! On the listservs we see requests for a supplemental needs trust form – as though there is no need to consider the nature and quality of care, choices, finances, and the future. If we do not plan for these, our documents may paper over or, worse yet, create as many problems as they solve.

To actually work, our documents must be user-friendly. They must be comprehensible (a high bar), accessible, and flexible. They must be accompanied by records and documents which we do not draft but which we can – and should -- guide our clients in preparing. It is these which personalize the trust and help people put its provisions to work for the individual we are trying to help.

So many things may happen.

Means-tested benefits may be cut back.

People receiving means-tested public benefits may inadvertently lose them through work, inheritance, marriage, or simply forgetting to promptly report a change of address.

We know that important non-means tested benefits will be cut. In 2024 Social Security retirement benefits, which also benefit Disabled Adult Children, will fall to about 79% of their current level; Medicare Part B will be insolvent; and Medicare Part A will pay only 83% of the current benefit. In 2033 Social Security is estimated to run short of cash. These changes may happen sooner as some people retire earlier than planned while others file for Supplemental Security Disability Income due to long covid.

Whatever may happen with public benefits, medical and long-term care cost increases will continue to outpace inflation. Private insurance as well as public benefit payment structures will continue to make it difficult to obtain sufficient care, whether by a physician, physical therapist, CNA, or community assistant. This will only be exacerbated by people leaving healthcare. A Washington Post-Kaiser Family Foundation poll published on April 22, 2021, reported that one-fifth of physicians and two-fifths of nurses plan to leave their professions in the next two years.

Self-reliance, that very American aspiration, is best complemented by interdependence and by dependence on a network of friends, family, neighbors, colleagues, and others. That is how we all get through life.

1. People

You and I draft and administer supplemental needs trusts to secure and maintain eligibility for means-tested public benefits. But if that is all we do, we fail the people we serve.

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