

## REFLECTIONS

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# Restoring the missing dimensions of care

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All my life I have been surrounded by family and friends who have provided a web of respect, trust, belonging, and encouragement. They have listened to me, believed in me – they have cared about me. I have taken all of this for granted; it has been a normal part of my everyday life.

Now, having spent a career spanning 35+ years surrounded by vulnerable children, families, and older adults, I've become very aware of just how important these “normal,” taken-for-granted aspects of my everyday life are, not only to my sense of self and well-being, but to everyone's.

I've come to realize that these foundational aspects of well-being — evolving from caring relationships with family and close friends — are rarely incorporated into policies, practices, or programs designed to address needs of

vulnerable people. They represent missing dimensions of care that services by nature can not provide.

## Experiencing vulnerability

Early in my career, I was researching the day-to-day experiences of families who had children from foster care placed in their homes for adoption; most of the families did not have the support they needed to parent these children who came to them with very troubled pasts. The result was that many of these pre-adoptive placements failed.

One day, after witnessing the return of yet one more child to “the system” by strangers (a police officer and a social worker who came to take him away), and removed from all that had become familiar, I had an epiphany.

What if it were my child who had been taken away by strangers and placed in the home of yet other strangers? It really is impossible to think about how we or our children would feel.

“Profoundly terrified”, “heartbroken”, and “helpless” all come to mind.

Twenty years ago I met an eight year old boy who had already been in eight foster homes.

He went on to live in 20 more. Recently having

been found not guilty of a crime and released from jail, he asked me, “Who do you turn to when you can’t count on yourself and have learned through experience you can’t count on anyone else?”

This week I had lunch with a dear friend, age 91, who only weeks ago moved into an assisted-living facility. How tiny her living space is; there is not even enough closet space to hold both a winter coat for church and a winter jacket for shopping. Meals are unfamiliar, “terrible” (according to her), and they must be eaten at specific times.

For these individuals, and for the growing number of people in the country who have lost or have never known independence, respect, or purpose — who can no longer or have never been able to help shape the story of their lives — their future is one of hopelessness and helplessness where what they do day-to-day depends primarily on decisions made by others, decision-makers who see them differently than they see themselves.

*Who do you turn to when you can't count on yourself and have learned through experience you can't count on anyone else?*

## Why does it have to be this way?

Timothy Shriver, in his just-published book, *Fully Alive*, writes that for people with intellectual disabilities, their vulnerability results in most of them living profoundly empty, lonely lives where they are viewed for what they cannot do and rarely, if ever, for what they can do.

Atul Gawande, in his recent book, *Being Mortal*, writes that people at the end of life often are treated as one more clinical problem rather than as someone whose life has meaning and dignity. Why does it have to be this way? As a country and as human beings, we must, and we can do better.

I believe that as individuals and as a society, we tend to look at those different from ourselves through a very narrow lens where the focus is always on what needs to be “fixed.” The result is that very little has changed for the ever increasing number of vulnerable people in this country.

When we ask ourselves how we would feel if a certain policy, program, or practice was being applied to someone we love, then we begin to think about “business as usual” in a different way. Certainly for the children from foster care I have worked with, policies and practices often severed what web of trust and belonging they might have had. And for older people with whom I work, when they need assistance with tasks of daily living, commonly accepted practices often force them to leave all that is familiar and much that is meaningful, stripping away their self identity.

*If we would not want a specific policy, practice, or program applied to our children or our parents, why would we want it for any other child or adult, especially those who are most vulnerable?*

## New standards

Clearly policies and practices are needed to address deficits and disabilities. But what about also addressing abilities, strengths, and goodness? To do this we must expand our understandings, perceptions, and expectations of people we consider “different” or “vulnerable.” With this, I believe, comes the responsibility for integrating into social services, as well as into future directions for supportive housing policy (nursing homes, congregate care facilities, foster homes, half-way houses), a new set of standards that

foster and support the universal underpinnings of well-being — sustained caring relationships that provide a web of trust, belonging, acceptance etc. — as a normal part of everyday life.

Aspects of these standards include:

1. People with vulnerabilities are viewed as *indispensable contributors* to the well-being of others;
2. Vulnerable people determine, to the greatest degree possible, how *they* want to be indispensable;
3. Programs and policies are based on *what we would want for our loved ones*, where compromise or deviation from the highest aspects of this standard would be a last resort; and more importantly,
4. There is recognition that among the things our loved ones (especially those most vulnerable) ask for is to have a “normal” life — however they understand that — and the recognition that their understanding may not be our own understanding.

## A new vision — a new normal

These new standards require a new mindset where people with vulnerabilities can, as Shriver has written, be fully alive — living life with “affirmation, purpose, and delight.” For those at the end of life, I would add living daily with dignity and a sense of peace and fulfillment. What is needed is a new vision of what is possible, of what can be.

*Just imagine what services, policies, and a community of caring people could achieve together.*

In addition to services and policies, a new dimension of care is needed where families and friends provide a culture of neighborliness — of friendship, kindness, helpfulness, and gratitude. Just imagine what services, policies, and a community of caring people could achieve together.

It will not be easy to create a “new normal” where services, policies, and neighboring share the same objective — to help people with vulnerabilities live life with “affirmation, purpose, and delight,” and where decisions evolve from the same basic principles that highlight what Gawande writes is the job of professionals, i.e., to address the reasons one wishes to be alive.

For the young man I met when he was eight, my own sense of what it means or feels like to have a normal life, to be fully alive, is unknown to him. He has had services, but never a web of family support, a sense of security or as he states, a positive sense of self. For my friend who is 91 years old, her sense of the familiar, of being of value — of living a life with joy and meaning, has vanished.

But there is hope – as one teenager at Hope Meadows told me:

*People tell me they are proud of me. For a long time everyone told me I was just a screwed-up foster child and that I couldn't do anything right... Now I'm living in this cool neighborhood where everyone talks to each other, and they get together for barbeques. It's fun and it's safe. I think of myself as normal here.*