

The Shape of a Marathon

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Normalization

There officially exists in California a philosophy of services that is based deeply in values. It submits that in order to grow, each person deserves:

- love, honor and freedom from stigma throughout life
- celebration of being special
- a life-sharing family, home and nurturing support
- a community of concern and friendship
- economic security, health and the full benefit of modern technology with a varied continuum of services
- freedom from the threat of injury due to pollution of food, air, water, and the earth on which we dwell
- the opportunity to grow, learn, choose, work, rest, play, be nourished, to experience well-being
- solitude when needed
- comfort and beauty in which to discover him/herself
- the power to improve his/her environment
- justice
- the dignity of risk, joy and growth of spirit
- a valid social future.

Such philosophy sums up many of the deepest held beliefs about quality of life. These beliefs are at the root of our current and emerging civil rights and human services laws and standards.

How any of us, as human beings, are perceived decides how we are treated in society. Our judicial system declared its stand to defend the virtue and inalienable accord for life: a commitment to change and growth, respect for each person based on individual identify, equality of opportunity, access to resources, full social integration, the right to privacy, the ability to exercise a voice in social affairs, and self-determination. These rights are rooted and interpreted from our constitutional guarantees. They have been translated over recent years and summed up in the principle of normalization in human service. This principle forms a bridge between ideas expressed in our ideal cultural values and their implementation in society's care-giving structures. Normalization in theory and operation offers a standard of minimum acceptability on which human services must be conceived, planned, provided, and judged.

Normalization advocates the use of means which are culturally normative in order to offer a person life conditions at least as good as those of the average citizen and, as much as possible, to enhance and support personal behaviors, appearance, experience, status, and reputation to the greatest degree possible -- at any given time for each individual according to his/her developmental special needs.^{1, 2}

Normalization insists upon accentuating the positive and eliminating the negative by doing everything possible to integrate people who have special needs into everyday lives so that they may enjoy all we value for ourselves.

Normalization dictates use of the least restrictive or drastic means to help people grow and change to avoid stifling personal liberty. This notion also applies to how we socially burden or enhance human beings with our labels, the use of technology, the location and appearances of the buildings and spaces where services are carried on, the image and impact of the kinds and numbers of service workers employed. All these influence how people served are seen and are decisive in shaping everyone's expectations, actions, and therefore the benefit or outcomes of service for individuals.

What is the best way to assist people in society to achieve and enjoy the fruits of that society? How do we assure not only that we do no harm, but that we uplift the persons we serve in the eyes of their fellow citizens? How do we balance the clinical or educational benefit of using methods that improve competence and performance with the cost in status and reputation of culturally stigmatizing measures? How do we protect the sense of personal well-being, confidence, dignity and pride of a person in an interdependent relation with services and staff who do not, or will not, identify with that person as a peer of equal worth? How do we recognize the right to treatment and help which each person possesses in our society, while eliminating ineffective programs which represent deprivations of liberty and impose overly restrictive alternatives? How do we implement the responsibility as teachers and caregivers such that, in the words of John Donne, "No man is an island, entire of itself; every man is a piece of the continent, a part of the main...any man's death diminishes me, because I am involved in mankind...."?

This anthology is already a history book, yet the experience and values addressed here are practically non-existent in the literature of developmental services.

This summing up of the state-of-the-art in the creation of lifestyle services paints a picture of what has happened in several places. It is up to us to garner the lessons of this search for excellence, and push forward to an even more civilized and humane future. Presented here is the tapestry of ideas and practice, woven together, one giving impetus to another in a progressive act of improvement.

Clearly, Nebraska with its ENCOR experience became the cornerstone for the fundamental challenge to North American human services. The uncompromising commitment to an ideology of service, developed in great detail as the principle of normalization, made almost everything that preceded it in the field obsolete. There is no way to fully measure the impact of such a contribution. It exploded the possible in the field through an idea, heroic leaders and a concrete model. The idea, like dandelion seed carried on the wind, spread to consumers, planners, teachers, service providers, advocates and researchers alike. If we do our job well, we may at least derive the following service benefits or actions:

- * Institution placements prevented
- * Persons returned from institutions
- * Emotional breakdowns prevented
- * Family breakup averted
- * Loneliness dispelled

- * Health preserved or restored
- * Services or social participation enhanced
- * Proper treatment provided
- * Persons habilitated
- * Dollars saved
- * Personnel needs reduced
- * Justice rendered or preserved.

We are still in the first mile, a mere decade, into a marathon that will stretch on and on towards the excellence of attainment and fulfillment. We can draw ourselves forward together into this demanding run. Tangible rewards of the race are reaped while we labor with both love and science to transform our society. Intangible intimate rewards of the effort are realized as personal records which are continually broken every minute of the way towards our common destiny.

It is in this spirit that this material is set forth. It is intended to create understanding of the continuum of appropriate help and living arrangement services needed for people with developmental special needs. It is meant to be a small commitment to common humanity and respect for every human being.

References

- ¹Wolfensberger, W. The Principle of Normalization in Human Services. Toronto, Canada: National Institute on Mental Retardation, 1972.
- ²Way To Go. Baltimore: University Park Press, 1978.