

Raymond's Room: Ending the Segregation of People with Disabilities

Dale DiLeo

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The Americans with Disabilities Act passed in 1990, yet according to the author this segment of the population continues to be discriminated against. And he should know, having spent more than thirty years in the field.

"I went over to observe, Al was brushing every child's teeth using the same tired-looking yellow toothbrush," the author writes. After that scene at a group home, DiLeo campaigned for, and won personal toothbrushes for each child. This unhygienic practice of toothbrush sharing would evoke disgust and cries of outrage in any other setting. That is his point: people with disabilities should not be subjected to different treatment than anyone else.

DiLeo is no renegade, having consulted with private and public agencies and trained thousands in the US, Canada, and abroad. He is the author of several books, including *Enhancing the Lives of Adults with Disabilities*. "People with disabilities," he writes, "are referred to fixed choices of programs...It is reminiscent of Henry Ford offering his Model T in 'any color as long as it is black.'"

DiLeo rails against the Disability Industrial Complex (DIC) named after the Military Industrial Complex (large, slow to change, and wasteful), after which it is modeled.

As the appointed lifetime founding member of the Association for Persons in Supported Employment's Emeritus Circle in 2006, DiLeo challenges the punishment-based "behavior modification approach," namely, denying individuals human contact, sunlight, and even food. Early in his career, DiLeo worked in a treatment facility for autism. There he met Raymond (the title's subject) who spent most of his days locked in a dark room as punishment for anti-social behavior. While he believes he failed Raymond, he does offer concrete positive outcomes. For example, a male client prone to excessive cussing and spitting found meaningful work in a loading dock where he fit in—to the amazement of his case worker. DiLeo refers to this modest success as "natural validity" defined as, "the extent to which something is acceptable to the cultural norms of a setting." He encourages a society of more independent living and working choices to enrich the lives of the disabled.

Professionals resistant to change may argue they are providing a service which no one wants to do. Those who work in the disability system are forced to continue in order to keep the gravy train of government funding flowing. DiLeo adds there is probably more incentive to not change. Without the medical labels, such as "autistic," programs for the disabled would cease to exist, as the money follows the disability. DiLeo exposes the true face behind the altruistic mask of governmental agencies.

GINNY WATERS (March / April 2000)

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