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(Serving the Disability Community of Oklahoma)

Raymond's Room, A Book Review

Dale DiLeo, author of *Raymond's Room: Ending the Segregation of People with Disabilities* offers readers some condensed insights into people with developmental disabilities which will challenge them to put away their pre-conceived ideas and take a fresh look. Mr. DiLeo takes off the blinders and brings his readers intimately into his experiences with people with disabilities over a long career. His understanding of and empathy with people with disabilities breathes passion into his case for tearing down attitudinal barriers which have in themselves limited people with disabilities for generations.

Raymond's Room was a real place, well-hidden from public view inside a residential facility for children with autism. This room was not much larger than a walk-in closet and was used to house children with "problem" behaviors. The stench from a room locked from the outside with a portable toilet inside was overwhelming. This room was referred to by staff as Raymond's Room because Raymond was the room's most permanent resident.

From this backdrop and inside view of how we housed and cared for people with disabilities in 1975, the author takes his readers through the looking glass of time down to the present to give us an historical perspective. We also look at the broad picture of all aspects of life for people with disabilities including home, work and play.

Mr. DiLeo spends a chapter looking at challenging behaviors which people with disabilities may exhibit in their efforts to be heard. Not only does he dispute some of the older, physically-punishing responses to challenging behaviors, he also points out where some of the more modern methods to control behavior may fail to address the real communication which the client with disabilities may be trying to express. He suggests that staff establish trust with clients before attempting to mold the behaviors which staff deem inappropriate.

Raymond's Room takes a big step in correcting myths which the general public has about people with developmental disabilities. But, it goes much further than this. It illustrates how those of us in the service-delivery system unwittingly perpetuate some of these same myths in spite of feeling that we are more enlightened than some in the general public.

The current slogan of "people first" is a common theme woven throughout the book. There is little doubt that many of us when we perceive an individual with disabilities tend to first look at the disability before we see the common humanity that we all have. This is a lesson for all of us—even many people who work with people with disabilities.

Mr. DiLeo coins a new phrase—the disability industrial complex. This phrase seems to be a take-off on an older term referring to the military-industrial complex which was used to describe American society from

the 1960's to the present. Many who used the second term were referring to a crushing "system" where the individual's needs were overlooked in order to perpetuate a system for its own sake.

The author seems to suggest that those of us in the disability field have also created a system which perpetuates itself rather than serving those for whom it was intended. Social service agencies are challenged to look at their policies to insure that we are building our policies to serve rather than to control. This book will prompt some serious introspection.

Raymond's Room reminds us all that people with disabilities have the same needs as everyone. They value privacy, accomplishment and interdependence. In short, they want a place in society just like everybody else. After our struggles with segregation when it referred to people of color, it appears we can take a further step in application of what we have learned to people with disabilities.

Learning to truly listen to people with disabilities is an acquired skill. Sometimes we continue to look at people with developmental disabilities as having deficits which it is our duty to "fix". We identify the deficit, and we decide how to correct these so-called deficits. Somewhere in this process, we may lose touch with what the person with disabilities wants. We are challenged to change some of our very basic attitudes which we may not even be totally aware exist.

What binds us to other people? What creates a sense of community? Mr. DiLeo points out that we have identities as belonging to certain groups. We may be a parent. We may be a voter. We may have an identity as doing a certain type of work. We may belong to a particular organization. Most of us have an identity in various groups, and the sum of all these identities defines who we are and how we fit into our community. People with disabilities are much more than the disability which we have.

Some of us are democrats, republicans, or independents. We come with various colors to our skin. We

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may be an auto mechanic, a cashier or a pediatrician. We are multi-faceted, and as people identify with us because they have a similar interest, a bond forms between us. We are connected. We do people with disabilities a service when we help them discover who they are in the broader world out there.

Mr. DiLeo emphatically reminds his readers of the importance of having a job which matches the interests and abilities of people with disabilities. Of course this is important to all people, regardless of ability. Workshops for people with developmental disabilities do not match people with a job which reflects their interests and abilities. The author objects to the use of workshops to serve people with developmental disabilities on the same basis he has used to object in every arena of life. They are segregated facilities which are separate but not equal.

Does this book talk about people with developmental disabilities, or does it talk about people with disabilities in general? I think the answer to that question is both. Is Mr. DiLeo qualified to write about the services of people with disabilities? I think the answer to that question is yes. He has worked directly with individuals with developmental disabilities. He has taught special education. He has been a director of an agency. He has been a consultant for agencies working with people with disabilities. He has worked in a broad spectrum of capacities.

Raymond's Room has a 2007 copyright by Training Resource Network, Inc. in St. Augustine, Florida. Its 212 pages read fast. For those of you interested in further reading, it comes with lots of references to other professional works. It may or may not be in your local lending library.