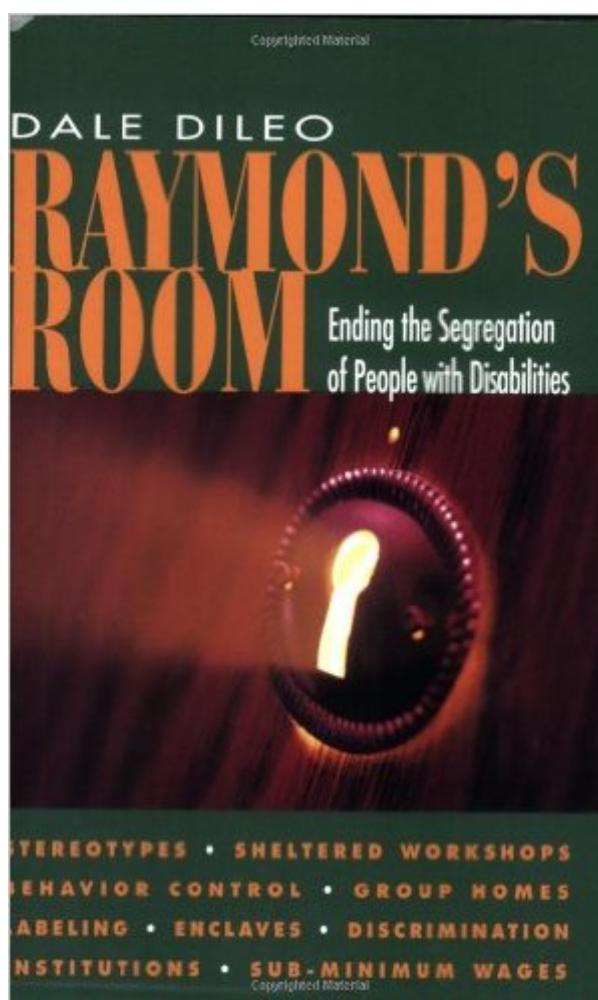


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# Raymond's Room: Ending The Segregation Of People With Disabilities



## Synopsis

Thirty years ago, as a young man working at a facility for children with autism, Dale DiLeo was shown a tiny, hot and smelly bedroom. Reserved for up to four young men with autism, those least trusted by staff, this room was locked--from the outside--all night long. It was named after Raymond, the room's perennial resident. Raymond's Room makes a compelling case that today, people with disabilities are still locked away from the rest of society. They may not be necessarily housed in rooms like Raymond's, but they are placed in facilities and programs run by a public monopoly unwilling to change. "People with disabilities are the last minority group in which legal segregation for housing and employment is still routinely provided," writes DiLeo. "And their lives are controlled by one of the last publicly-funded monopolies in America today." Using research, anecdotes, and heartwarming stories, DiLeo takes aim at the billion-dollar "disability industrial complex" that segregates people with significant disabilities from mainstream life. Calling people with disabilities society's "hidden citizens," he describes a system that prevents people from working and living in our communities, despite new techniques and approaches proven effective in helping even those with the most serious challenges to be employed and to have a home to call their own. DiLeo describes the downsides to current practices in the field and then offers up proven alternatives.

## Book Information

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## Customer Reviews

When activists in the 1960s exposed the horrific conditions of Willowbrook, a New York institution for people with disabilities, progress began to be made on the reform of such conditions. As he

describes in his book *Raymond's Room: Ending the Segregation of People with Disabilities*, when Dale Dileo started working with people with disabilities in the mid-1970s, he discovered that in spite of a greater awareness by the public, high-profile politicians calling for change, and the publication of books and broadcasts of television shows about conditions in institutions, the conditions still were poor at best, and, in some cases, horrifying. Dileo gradually came to take the position of Gunnar Dybwad, who wrote that "Four decades of work to improve the living condition of children with disabilities has taught us one major lesson--there is no such thing as a good institution." While still a college student, Dileo got a first-hand glimpse of one small way institutions dehumanize people with disabilities. At the residential school for children with autism he was shown that, among the many indignities, one staff member brushed all the residents' teeth--with the same toothbrush! Then he met Raymond, who, on a nightly basis was locked in a small room which was stifling in the summer, freezing in the winter, and that reeked, due to the use of a portable toilet in the room. The staff would lock the door from the outside, leaving him there all night. As a young staff member, Dileo was shocked, but never did anything to change this policy. As his views changed over the years, he came to reject the whole philosophy of institutionalization, and worked to get the Raymonds of the world out of institutions altogether. People with disabilities have long been isolated and segregated, primarily by institutionalization, which almost inevitably leads to horrible conditions, as well as, at the very least, "needlessly limiting the quality of life for the residents that live there." Some of the problem Dileo attributes to what he calls the disability industrial complex (DIC). Just as President Eisenhower described the military industrial complex, Dileo argues that the DIC is "a mega-system whose primary goal is to perpetuate itself." The DIC is "vast and complicated, often self-serving. . . . It is a huge industry, aided by government-sponsored grants and often costly technology." Like any bureaucracy, the DIC has a tendency to centralize and categorize. It has a preference for segregated institutions, labeling people and placing people with the same label together. This categorization and segregation hinders social development and the acquisition of skills needed to be a part of society as a whole. Dileo specifically addresses sheltered workshops as an egregious example of the shortcomings of the DIC. In these workshops, participants perform simple, sometimes completely pointless tasks, for a very low wage, pennies a week in some cases. The employer will contract with an agency of the DIC, who will provide supervision and training for the workers who have disabilities. There are many problems with this system. The workers themselves get nothing close to minimum wage, but the labor department considers this to be OK. Rarely do the workers learn skills that can be applied to a job in the open market. Even though they may be working in a workplace that employs non-disabled people, they often have little interaction with other

employees. Finally, the job they hold is not their job; it's a job to be filled by someone--anyone--the DIC agency provides. Thus, the worker does not build a sense of job ownership and accountability. Dileo provides several examples of individuals with disabilities with whom he has worked who work in an open-market job alongside people who do not have disabilities. The key is to look at the individual with disabilities as someone with unique skills. Our tendency is to place the disability front and center. Instead we should look at what someone can do, and find a place where his skills can be useful, where he can be productive. Sheltered workshops, favored by the DIC, tend to perpetuate segregation and do not typically lead to mainstream employment. Another DIC favorite is the group home. While in most cases a step forward from the large institution, group homes tend to be much less like homes than programs. Residents in group homes have little self-determination or control over the way they live. Meals, group outings, schedule, even the setting on the thermostat, are determined by staff, limit choice and independence of the residents. As much as possible, people with disabilities should be able to work toward self-determination, as we all do, by finding independent living and mainstream employment as much as possible. The central theme that I picked up on in Raymond's Room is the necessity of community. Dileo did not address this explicitly, but it was implied in every proposal he made. The success stories he relates frequently include a coworker or neighbor or friend who comes alongside someone with a disability to encourage her or train her or simply give some advice or a kind word. When someone with a disability is an active, present part of a community, his neighbors and coworkers will be more likely to offer assistance. By contrast, when someone with a disability only gets out in the community as part of a large group on an outing, there is no opportunity there for relationships and community to develop with those who are not disabled. Lest his critics jump on Dileo for wanting to push people with disabilities out the doors of institutions, I think Dileo would argue that he does not want them entering society with no safety net. Dileo wants for his friends and clients and neighbors with disabilities what we all want: a community in which I am valued, to which I make a meaningful contribution, and in which I am sustained by and sustain others with bonds of friendship and community. That is the greatest challenge of Raymond's Room: many of us tend to remain isolated from community. We pay a price for that, but not as high as price as someone with a disability who is living on his own. Is there a disabled neighbor or co-worker or fellow church member who could use my encouragement, guidance, or assistance? Unless I am will to play a part in the life of someone with a disability (as Dileo certainly has), it would be disingenuous of me to embrace and promote Dileo's thesis. I am convinced he is right, that the segregation of individuals with disabilities in institutions, group homes, and sheltered workshops must end, but it cannot without a community

that will embrace those individuals.

This book has some very good information on the disabilities field and I plan on using it in my introductory course on disabilities. However while the author rails against the Disability Industrial Complex (DIC), he does not stress enough the real problem with services to people with disabilities in this country: their de-valued status which results in inadequate funding, low pay for service providers and extremely high turnover. There are too many "experts" in this field who have left management and direct service to become consultants; resulting in what could be called a Disability Consultant Complex (DCC). So while they may fill hotel meeting rooms for their presentations about what is wrong with the system, the reality is over half the people that attend these sessions will leave the field within one year's time. If more consultants stayed in the field to direct services, advocate politically and practice the philosophy, the service system could improve. There are simply too many people "talking the talk" in the disabilities field.

Raymond's Room points out the terrible truth that in so many communities, people with disabilities, served by the most richly funded disability system in the world, remain victimized by the soft bigotry of low expectations. Dale rightly points out it is time to admit we're stuck and start doing business very differently! This should be required reading in all high schools and colleges across the country!

One of the great hidden scandals of our time is the treatment of people with significant disabilities, who are subjected to actions and practices that for any other group would be considered disrespectful, prejudicial, abusive, and a clear violation of fundamental civil and human rights. Yet, the existence of such practices is either ignored, or worse yet, considered acceptable. "Raymond's Room" sheds some much needed light on this issue, and does so in a way that is truly engaging and thought-provoking. Dale DiLeo is to be applauded in his willingness to pull no punches in his critique of the all too often dysfunctional service system, as well as his own self-reflection and self-criticism regarding his role within this system. This book is a call to action for all social justice and human rights advocates, as well as a must read for anyone who considers themselves an advocate for people with disabilities.

What a wonderful book. As a disability support worker I find it truly sad to see the abuse in the area of disabilities. I recommend this book to any student or worker in community services. Thanks again books for allowing great books to be available.

Because my career has paralleled Dale DiLeo's, I can testify that he's got it right. Thirty years ago many of us were inspired by leaders in the disability field who provided a vision for change based on a combination of the latest research and the civil rights movement of the 60s. What happened? Progress has been made incrementally, instead of the expected broad shifts in perspective. Federal law has provided direction, but the states have failed to implement the intent of federal legislation. Why? The disability services bureaucracy AKA the DIC (Disability Industrial Complex) has their fingerprints all over it! Thanks, Dale! FREE OUR PEOPLE!

Great book for anyone interested in folks with intellectual and developmental disabilities. I use it as my supplementary reading for a class for job coaches and job developers. Students who have read it have indicated it has given them a better understanding of the need for inclusion.

For years, people with disabilities have been invisible in our society--RAYMOND'S ROOM puts the fire in us to make sure this doesn't continue--let's follow the advice given and look at people for their abilities and make sure that everyone has an opportunity to belong in a valued way--Kudos to Dale DiLeo for writing the consummate book on this subject!

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