Clarion Review

Health & Fitness

They Created Us: Special Education, Medicaid Waivers, EPSDT, Independent Case Management - A Family's Journey Through a Bureaucratic Maze!

Denise Mercado
978-1-4259-7070-3
Four Stars (out of Five)

Every parent has high hopes for his or her children and spends a lot of time imagining what the future is going to be like for them. When a child is born with developmental disabilities or develops them later in life a parent's hope is changed into a need for action and support that's not always available.

Denise Mercado knows all about that sudden shift from normal parent to activist. Her son Danny contracted a rare form of meningitis when he was six months old which lead to cerebral palsy and other severe health and developmental issues. Danny has never spoken walked or done any of the things most children do.

In the beginning Mercado and her husband relied on people in their community to help them care for Danny. As time went on this military family realized they needed more assistance and found themselves mired in bureaucracy frustration and funding dead-ends.

They were given incorrect information not made aware of programs that could help them and denied support that by law should have been available to them. The more they learned about the way disabled children are treated the more they realized their story was not unique.

"The bureaucracy in its wisdom operates through committees and unending meetings" Mercado writes. "But change will only take place when the bureaucracy takes the time to listen to the people it serves. The bureaucracy must be willing to meet families where they are. It must be willing to leave the state capitol and meet with families in their homes and observe their surroundings and the sacrifices they make and the struggles they endure."

This heart-wrenching book describes the struggles of the Mercado family and others who have developmentally disabled children in North Carolina in great detail. In fact there is so much detail so many long quotes from e-mails and reports specific to the situation in North Carolina that it might not be as useful to parents outside of North Carolina.

Still as a guide to show parents of disabled children and adults how one family has tried to work through the system its successes and failures and all the roadblocks stumbles and victories along the way.

This book will outrage people who care about the treatment of disabled people in America. For parents of disabled children this book should give basic information that will help them no matter where they live as well as details that should inspire them to fight for their own children as Mercado and her compatriots have fought for their children.

Sarah White