Book Review: *Far From the Tree*

[**Danny van Leeuwen**](http://www.jopm.org/author/dvanleeuwen)   
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Abstract

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Andrew Solomon’s *Far From the Tree: Parents, Children, and the Search for Identity*[[1](http://www.jopm.org/media-watch/books-literature/2013/02/18/book-review-far-from-the-tree/#footnote_1)] covers stories of diverse caregiver experience; parents with exceptional children: children with deafness, dwarfism, Downs syndrome, autism, schizophrenia, or disability. Others are caring for children who are prodigies, transgender, conceived from rape, or committing crimes. It is a rich and exhausting tome (962 pages) — profoundly sad, exhilarating, and inspiring. Solomon interviews more than 300 families navigating a journey they didn’t choose, caring for their children, facing unexpected challenges. What can those of us committed to participatory medicine learn from their experience?

Actually, their experiences sound somewhat familiar. Many of the stories walk us through the stages of grief: denial, anger, bargaining, depression, and acceptance. In addition, we observe the stages of exhaustion and expansion (thanks to [Durga’s Toolbox](http://www.durgastoolbox.com/)). Expansion is the celebration of walking through doors not present before: new communities, advocacy, and personal growth. The medical experience is common for all the groups of exceptional children, and we of [SPM](http://participatorymedicine.org/)know of those challenges. Yet, as we know, much of their health journey is social, cultural, financial, and historical. Solomon addresses the mechanisms and key success factors of patient-professional partnerships, patient engagement, care coordination, shared decision-making, peer-to-peer relationships, and social determinants. What he concentrates on is the dynamic tension of identity, belonging, and community. Identity and community changes for these families with unexpected challenges. The deaf community is strong and supportive, yet can be exclusive. Passions run high about cochlear implants. Dwarfism was once shameful and isolating; now the community is strong and struggles with society’s definition of dwarfism as a disability. Developmental, mental, and physical disabilities consume families. They need so much help. Each child is on a spectrum from profound effects to much less. Parents coping skills vary. Their understanding of the child’s individuality, mysterious within the disability, affects their ability to plan and advocate on behalf of their child. Those children whose care has a pattern or rhythm can be more manageable than those with unexpected fluctuations, as with schizophrenia.

The chapter on transgender children increased my awareness of the complexity and layers of challenge for these children and their parents. As a child of a closeted gay father and straight mother, I have a set of experiences that helps me empathize about some family tensions, but does not provide a window into some of the more harrowing aspects of these experiences — identity issues, medical challenges, relationship dilemmas, and on and on.

Frankly, I couldn’t read this entire book. The chapters on the children of rape and those committing serious crimes so upset me, I cried choked, and abhorred. The violence of rape is beyond my ken. The loneliness of some of the victims of rape and the parents of children committing serious crime overwhelmed me. I skimmed these chapters.

My focus in health is to find the magic levers of best health. What are the small actions that can make an outsized difference in the personal, organizational, and societal journey to best health? What does *Far From the Tree* add to my appreciation of magic levers? Well, it confirms the basics: diet, rest, love, a participatory team with the patient at the center, supportive community. It adds identity and choice as magic levers. Identity is belonging, self-confidence, centeredness. Choice honors the complexity facing parents and their exceptional children. I have to ponder choice more.

This book peeled back the personal, historical, cultural layers of caregiving in a manner that has forever shaken my perspective about best health. I’m thankful to my friend, Carrie Mauras, from the Autism Friendly Hospital initiative at Boston Children’s Hospital for giving me this book. I highly recommend the book if you have a strong constitution, and are willing to have your fundamental views and values be shaken and challenged. Honor the caregivers. Help the helpers.

Reference

1. Solomon A. [*Far From the Tree: Parents, Children, and the Search for Identity*](http://www.farfromthetree.com/). New York: Scribners; 2012.

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