

Invited Paper

Pure grit: Ordinary and extraordinary

Matthew MacCarthy*

Department of Pediatrics, University of South Carolina and Prisma Health Children's Hospital, Columbia, SC, USA

Received 24 January 2024

Accepted 15 February 2024

Keywords: Disability, cerebral palsy, sport, lifespan, lived experience

At the 2018 Annual Conference of the American Congress of Rehabilitation Medicine, I presented a portion of a symposium discussing gait analysis, pain, patient-reported outcomes, and adaptive sport in individuals with cerebral palsy (CP) [1]. It was titled “Overcoming Pain and Disability in Cerebral Palsy: A Mentored Clinical Scientist Symposium.” When we tried to spread interest on social media, one user gave constructive criticism that the word ‘overcoming’ was offensive for the disability community. As someone living with CP, I was surprised and a bit ashamed to learn this for the first time at 33 years old. And while my fellow presenters and I obviously did not intend to offend anyone, I have paid closer attention to language since that time. I was brought back to this moment, pleasantly, by *Pure Grit: Stories of Remarkable People Living with Physical Disability*, the introduction of which explicitly states, “These remarkable individuals are not *overcoming* disability – they are accommodating disability in their lives while pursuing their dreams” [2].

What follows are 19 personal stories of people across the physical disability spectrum who have achieved notable success in various fields, told in a mixture of first and third person points of view and free from judgment, interpretation, or extrapolation from the authors. Visual impairment, congenital and acquired limb differences, CP, spina bifida, spinal cord injury, achondroplasia, and muscular dystrophy are represented among athletes, politicians, government officials, doctors, scientists, and lawyers. CP and Paralympic swimming are overrepresented, the former being the most common motor disability of childhood, and the latter “reflecting the popularity of swimming as a sport of choice for people with a physical disability” [2]. This also makes sense for coauthors Lily Collison, author and mother of an adult son with CP, and Kara Buckley, Senior Advisor to the US Olympic and Paralympic Committee.

The stories include vignettes and narratives from early life, education, and career(s) of each individual, with disability specifically and intentionally out of the spotlight. Emphasized again and again is the fact that having a disability does not make one special, exceptional, or inspirational, but rather that these traits come through one’s actions, attitudes, and contributions. I wouldn’t have expected anything different from authors with this kind of exposure to the dis-

*Corresponding author: Matthew MacCarthy, Department of Pediatrics, University of South Carolina and Prisma Health Children's Hospital, 9 Richland Medical Park Dr, Suite 410, Columbia, SC 29203, USA. Tel.: +1 8034341824; E-mail: matthew.maccarthy@prismahealth.org.

ability community, but the overt attempt at avoiding the disability inspiration narrative is a tremendous positive by itself. In addition to being inundated by it in media, many people with disabilities have been the subject of this at some point – I have been called an inspiration for using the elliptical at the gym.

Unsurprisingly to many of us in the disability community and in rehabilitation medicine, recurring themes emerge among the interviews. My all-time favorite soapbox is ubiquitous from chapter to chapter, with medical professionals telling parents that their child ‘can’t,’ ‘won’t,’ and ‘will never.’ Every medical student, resident, and fellow I’ve ever taught about anything related to disability has heard that absolutes should be avoided, especially for conditions like CP, which have such a massive spectrum of clinical presentations. There is certainly a great deal to be said about medical communication and what is said versus what can be interpreted by stressed and grieving families, but I consider the use of absolutes like these an invitation to be proven wrong. And many of the individuals highlighted in this book are quoted as saying that they were motivated by exactly that – proving us wrong. Whatever their chosen path, many talk about experiencing irreplaceable freedom while doing what they love – whether in the air, in the water, on the track, or in the office.

Parents and support systems are discussed a good deal, whether they be friends, coaches, teammates, or role models, the latter of which are joyously becoming more common as stories like these are shared, representation improves, and dissemination of events like the Paralympics become more of a global priority. We repeatedly read about parents with high expectations who refused to shelter their kids, with the interviewees themselves commenting on not being ‘bubble wrapped’ and instead having their aspirations supported, often against significant adversity. The individuals discussed range in age from their twenties to their seventies, so the older ones had to forge uncharted territory. Among those is Judy Heumann, the legendary disability rights activist who has since sadly passed away.

Then come the stories of the things people actually had to *overcome* – among them, societal, attitudinal, and physical barriers. The naysayers extend well outside of the medical community. School systems sometimes weren’t, and aren’t, equipped to adequately serve people with disabilities. Job interviews, if they are even offered, are rife with invasive and inappropriate questions. Assumptions abound, and as we all know, physical accessibility is an enemy

unto itself. Discussion of injustice is where most of the book’s focus on disability is found; this drives home the fact that most of “overcoming disability” is not about the impairment but about learning ways around a system that still has a long way to go toward the dream of equity.

Mentioned repeatedly by the Paralympians in the book – but no doubt felt by all of us – is the desire to be seen and known for achievement rather than for disability, or for achievement with a footnote in which people are categorized separately because of their disability. Daniel Dias, a highly decorated Brazilian Paralympic swimmer, has been called “the Michael Phelps of the Paralympics,” to which he responds, “No, I’m the Daniel Dias of the Paralympics.” The Paralympic classification system is discussed by the athletes, and while I am not knowledgeable enough to offer any insight here, most seem to feel there is still room for improvement. It seems ironic to emphasize the need to celebrate achievement without footnotes when discussing a book exclusively about people with disabilities, but the book could just as easily, and just as effectively, have been about life lessons from 19 highly accomplished people who faced any kind of adversity. Which is to say, it could have been about 19 stories from almost anyone on Earth who is highly accomplished. And that’s the point.

Listing the anecdotes and quotes that I found useful and insightful would take an entire article by itself, but suffice it to say that there is a lot here from which to learn, and a lot to appreciate regardless of your relationship to individuals with disabilities, be it family, advocate, provider, or self. The highlighted individuals offer advice and perspective to doctors, families, and society at large. Particularly exciting for me to see were the multiple people adamant that transitioning to a wheelchair was not a tragedy or loss but rather a gain of independence and self-determination, which myriad families would benefit from hearing.

There are some who may say I have grit. Personally, I think a lot of opportunities have been handed to me. But I will never tire of hearing stories of those who inarguably know how to get back up after they fall. And the world needs to know that disability doesn’t prevent people from being truly extraordinary.

Author disclosures

No disclosures.

References

- [1] Thomas S, MacCarthy M, Tow S, Carollo J. Overcoming Pain and Disability in Cerebral Palsy: A mentored Clinical Scientist Symposium. Symposium presented at: 95th American Congress of Rehabilitation Medicine; 2018 Oct 30 – Nov 4; Dallas, TX.
- [2] Collison L, Buckley K. *Pure grit: stories of remarkable people living with physical disability*. St Paul, MN: Gilette Children's Healthcare Press; 2021.