A Father's Chair: Reflections on Media, Disability, and Fatherhood

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Disability and the Family
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ABSTRACT

In the following paper I use a form of disability memoir and personal narrative to expose a gap in parenting literature and disability representation. For decades, the scholarship of Disability Studies has argued for greater and more accurate representation of people with disabilities in all media forms. However, these types of representations remain absent from parenting literature, and parenting narratives. This is particularly evident in the absence or reduction of fathers in these spaces. Therefore, I use my own story and experiences as well as examples from film, television, and popular parenting texts to highlight the types of changes that would be beneficial.
Adequate and accurate representation of people with disabilities has always been a key aspect of the work that Disability Studies has done over the last 40 years. Not only are we as scholars interested in seeing people with disabilities in films and on television, but we also want to see those representations fairly reflect the strengths that we have and the realistic lives that we live. In the story that follows, I engage in a form of disability memoir in order to demonstrate a fundamental gap in the representation of disabled bodies – and more specifically disabled fathers from parenting literature. According to G. Thomas Couser (2008, p. 191), for people with disabilities, using memoir has:

the considerable potential to counter stigmatizing or patronizing portrayals of disability because it is a medium in which disabled people may have a high degree of control over their own images.

Also, as I have tried to teach hundreds of students through the years, direct examples and evidence make abstract ideas concrete. It would be one thing for me as a disability scholar to offer a lament about the absence of fathers with disabilities from any given space. I could also comment more directly on the negative ways children with disabilities are portrayed in parenting literature and stress that when writing about the interactions of disability and the family, early representations of these relationships focused on parents as caregivers for children with disabilities. However, British disability scholar Tom Shakespeare (2006, p. 188) reflects on that work and concludes:
In stressing the negative aspect, there is a danger of giving an unbalanced picture, and failing to see all the good and hard work which parents of disabled children do. Parents are almost always the primary carers of disabled children: they help them through encounters with doctors and hospitals, they support them through education, and try to enable them to make a successful transition to adulthood. Parents also suffer when they see their child suffer.

It is therefore altogether different when I can imbue my argument with the personal struggles that I myself have faced – not because these are somehow more poignant than others I might identify, but because if I do my job well enough I can bridge the gap between writer and reader so that my experiences are truly shared. To paraphrase Linnea Franits (2011, p. 129), fatherhood and disability have always been inextricably intertwined for me, and so I hope that the intersections prove valuable as I outline a complex narrative.

To do this, I share first my own narrative of disability, as a child growing up with cerebral palsy and then the details of my search for appropriate literature that would offer ways for me to interact with my newborn son when we discovered that my wife was pregnant. Thirdly, I reflect on the entirety of the journey so far in order to demonstrate some of the lessons I have learned along the way. Lastly, I suggest that this paper is only the beginning of a new research area for disability scholars.

Before I begin, however, I must acknowledge that although the very nature of Disability Studies discourse and disability memoir reject the very notion of usurping the voices of individuals to tell their own stories, at least some sections of what follows belong to other members of my family as well as myself. However, my story is so deeply
intertwined with the people who have shared my life that it is difficult to separate them, and so I owe a debt of gratitude to them as well.
GROWING UP

The most comfortable chair in my parent’s house was an old brown recliner that sat in the corner of the living room. It was positioned next to a lamp and a bookcase that had its top shelf covered in golfing trophies and tees, while the other two shelves were brimming with paperwork. The smell of pipe tobacco mixed with Gillette aftershave and the sweat from a hard day at work greeted anyone who sat there. It was a great place to read, and perfect for a nap. This was Dad’s chair. All of us always wanted to sit there, but if there’s one thing that sticks out from my childhood more than any other, it is that no one ever sat in Dad’s chair when he was home. He worked a fourteen hour day at a hardware store six days a week, and the one thing he wanted when he got home was to sit down and read the evening paper from cover to cover – dinner was a distant second.

Mom worked too – she was a beautician and had a shop in the house. This way, she always knew that someone would be there when one of her six kids returned from school. I remember Mom juggling her customers, sporting events, band, orchestra, and chorus concerts, along with dinner every night. I have no real concept of how she did it. What I know is that they did it the best way they could, and quite possibly the only way they knew how.

What I find truly wonderful about this is they were able to do all this regardless of my disability, and the extra tensions and activities that I know it added to their lives – to all our lives, really. What I know is that despite their sometimes over-protective natures, my parents never allowed cerebral palsy or wheelchair use to get in my way. I also know that they did all of this without relying on books for the majority of their information – they were far too busy, and tired, to read. Dad’s role models for fatherhood, if he had
any, were the guys he worked with, the guys he saw in the neighbourhood, and maybe, just maybe, the examples set by Jim Anderson, Ricky Riccardo, and Mike Brady.

Mom and Dad didn’t need books, they needed and received the support of family, friends, and government programmes, though I didn’t know it at the time. My parents seemed to take solace in the common idea that “it takes a village to raise a child”, and I distinctly remember neighbours arriving on a weekly basis to help Mom perform the exercises that research had said would strengthen muscles, teach my muscles the movements associated with walking, and work to re-establish the neural connections that were faltering between my brain and my body. Though none of these techniques proved to be the miracle cure that the 1980s seemed to always promise, the ways that my neighbourhood came together taught me my own importance as an individual, and demonstrated that disability didn’t matter as much as friendship did.

As Tom Shakespeare suggests (2006, pp. 188-189), my parents worked hard to make sure I had the things I needed, and throughout my teenage years I built an incredibly strong relationship with my Mom as we travelled together to doctors and therapy sessions. I always knew that Mom wanted the best for me, and I also knew that she and Dad were doing everything they could to mainstream my life. Aside from having a typewriter for classwork, an accessible desk, and a one-to-one aide that would assist in the transition between classes, my school experiences were shared with the rest of my graduating class. The friendships I made there were long-lasting and honest, and many of these friends (and their families) adapted to my needs quickly and easily. It was not uncommon, for example, for me to visit other houses not equipped for wheelchairs. In those cases, I would be lifted up the necessary stairs, and be carried inside. Once my
chair was unfolded, I would manoeuvre as much as possible, experiment and challenge what was difficult, and finally be content with what I could not do.

These moments and others helped me to develop the sense of independence that I have today, and I was always taught that I could succeed if I had the right tools. When I left for college, therefore, my single and primary concern was not one based on academic success, or the inevitable difficulties that would arise while trying to navigate snow-covered hills, but rather the personal embarrassment that would ensue given a set of circumstances no one could control.

Throughout my life, I have successfully navigated several college experiences, and spent time as a computer programmer and a university English instructor before I was married and started my own family. By then, I had witnessed plenty of family members and friends raise children, and had seen many behaviours to borrow, but I had not yet found a role model that parented while having a pronounced physical disability or found one who used a wheelchair to aid them in matters of mobility.
Role models are important in life, and I don’t just mean the posters that we put up in our bedrooms as teens when we have stars in our eyes and want to be the next Michael Jordan or Britney Spears. I am referring to the people after whom we model our daily behaviour – the people who shape our daily decisions in ways that they may not even realize, and the people we want to emulate because they are already a lot like us, but better, and smarter. These are the realistic role models that shape the people we become in our lives, and these are the people that I was seeking when a doctor told my wife and me that we were expecting a child.

During my wife’s pregnancy, I scoured the shelves of local booksellers and libraries for anything to read alongside *What to Expect When You’re Expecting* (Murkoff & Mazel, 1994) and *Great Expectations: Your All-In-One Resource for Pregnancy and Childbirth* (Jones & Jones-Brennan, 2004) that paid at least some attention to fathers as something other than a doorman in the whole process. Beyond that, I really wanted some practical advice on negotiating my son and my disability at the same time. How, for instance, was I to change a diaper in the early years? Could I honestly be present for my family in a productive way? As a new father I was concerned – all right, scared – about the ways in which I could interact with an infant. I also needed to know that I was not alone.

Many of the books we found focused on the mother-to-be, and resigned Dad to positions reserved for support staff. My inability to walk made it difficult to rely on me to retrieve the stereotypical pickles and ice cream at two in the morning, or carry the bags...
to the hospital, so I did not find myself represented well. However, this is a technological age, more interested in the moving electrons of the internet and television rather than the stationary ink of print, so I also looked at the large and small screens to find my fatherly icons. Here, I found comedians like Bill Cosby and Ray Romano, Tim Allen and John Goodman – the fathers of the new generation that had learned from Desi Arnaz, Robert Young, and Robert Reed themselves, just as my own father did. The problem was that none of these kids were still in diapers, and none of their parents used wheelchairs or had any discernable physical limitation at all, with the possible exception of an episode on crutches now and then. These comedies and actors certainly made family life fun, poignant, and often wrapped it up in a nice morality coloured ribbon, but the practical solutions I sought were not found here either.

Silver screen representations of disability are much more frequent, and stories of parenting and families are common too. Therefore, it made sense to screen movies like *Kramer vs. Kramer* (1979) and *Mr. Mom* (1983) which presented narratives of dads trying to do what society saw as Mom’s job. Audiences no doubt learned about the importance of a father’s narrative and voice, but nonetheless wanted to see him back in the traditional breadwinning role. Here, physical differences were being traded for social ones. The fathers were socially disabled by the fact that they have to participate in new ways with their kids, and at least temporarily remove themselves from wage and salary earning positions. Movies that dealt more directly with disability such as *Whose Life Is It, Anyway?* (1981) and *The Waterdance* (1992) were designed to showcase the parent caring for a child with a disability – thereby rendering the disability itself as problematic and the child as helpless. In these two movies, however, the parent-child relationship
was established by virtue of friends and family coping with a new disability in their midst and infantilizing the main character with the disability. While I was gratified that moviemakers were representing disability on screen at all, I could not truly identify with these plots as a parent.

Still searching, hope appeared when I saw a screening of *I Am Sam* (2001) starring Sean Penn. As a young father with a cognitive impairment, Sam (Penn) struggles to raise a newborn daughter on his own. In the process, he utilizes the help and expertise of neighbours, friends, and employers to reach his goal, but he does so on his own terms, learning and adapting the whole way – just as any new father would. The crux of the plot is not to watch Sam learn about how to raise Lucy, but rather to watch the rest of the characters and audiences learn about fatherhood. The government challenges Sam over his right to keep and raise his daughter, and it is in that process that we learn about Sam. For me, the movie represented everything that I had been looking for, until the “inappropriate father” story took over the plot. By that point in the movie, however, I would hope that the audience had identified enough with Sam so that they were in fact rooting for him to succeed. This movie signified a major shift in the way disabilities and the people who have them were portrayed on screen.

As I noted above, representation is a large part of the work that disability scholars do, and the fact that I did not find exactly what I needed on television does not negate the work that has been done. Through the patience and dedication of committed writers, actors, directors, producers, activists, and scholars, the representation of people with disabilities has skyrocketed. As those people will admit, however, the battle only starts there, and we become victorious only when adequate and accurate
representation occurs. This must include fathers not resigned to the roles of decades past, but rather (re)presented as the equal partners that many are. This is by no means an easy task, and will take all of us standing on the shoulders of those who have come before, and those who are working now. In a book that helped define the work of Disability Studies for the new century, activist and scholar Simi Linton (1998, p. 25) wrote of disability representation:

Some of the stereotypes that are particularly entrenched are that people with disabilities are more dependent, childlike, passive, sensitive, and miserable and are much less competent than people who do not have disabilities. Much of the language used to depict disabled people relates the lack of control to the perceived incapacities, and implies that sadness and misery are the product of the disabling condition. These deterministic and essentialist perspectives flourish in the absence of contradictory information.

The stereotypes that Linton mentions are not simple representational issues confined to movies either. These become ingrained in the minds of the public at large, whose members often find it difficult to reconcile fact and fiction. Working in Disability Studies for as long as I have, I was of course aware of this, but the reality of the pervasive nature of this thinking was demonstrated very clearly in the delivery room when my son was born.
MOMENTS OF TRUTH

Many television shows, movies, and books describe that moment in the delivery room when a father gets to cut the cord of his newborn child. That was not a moment I wanted or needed. My wife and I had discussed it far in advance, and I had told her that it was more important for me to take care of her at that instant than to risk one of my tremors at the wrong moment. It’s not that I didn’t want to enjoy the moment of our son’s birth, but I knew that my focus and energy would best be spent on the person I knew I could support well – my wife. Therefore, my presence in the delivery room meant a great deal. However, the idea of a wheelchair in the delivery room seemed so foreign to the staff where we were, that I was very quickly moved into a position that was away from the position where I knew I could help, to one where I could do little but watch a show I did not particularly want to see. Of course this was done for her safety as well as my own, and of course I wasn’t going to argue publically about the kind of sense it made in the moment, but in the spirit of that honesty, I will also admit the pain I felt at being denied the one moment when I actually was prepared to take an active role in the process – that of keeping her calm in ways that I knew the others in the room could not. As friends joined me on the journey home that night, I relayed the story, and compared my own experience to being treated like a piece of furniture.

These feelings were recreated several times throughout the first six months of our son’s life, but most noticeably only days later, when the hospital’s lactation consultant was explaining certain techniques to both of us, looked first at my wife and then at me and asked her, “Well, you’ve got a great baby-sitter there, but what are you
going to do when there’s real trouble?” Even though I was offended by these remarks, I did not say anything because the thoughts behind them struck too close to my own fears. My wife, however, was not as quiet, and reminded our instructor that I was in fact more than a sitter, more than a donor, and that I was in fact our child’s father. When she emphasized the last word, I heard a respect in her voice that I had not yet heard from others during the process.

Nevertheless, this encounter renewed my interest in finding narratives that demonstrated the ways that fathers with disabilities participated in the early stages of child care, and in the years since our son was born, I’ve seen a plethora books written by dads for dads -- each father detailing the promise and the pitfalls of the job. The ones we found most fruitful were: Armin A. Brott’s series on fatherhood (Brott & Ash, 2001; Brott, 2004; 2005), Crawling: A Father’s First Year by Elisha Cooper (2006), and two books by Robert Wilder titled Daddy Needs a Drink (2007) and Tales from the Teacher’s Lounge (2008). Fathers of every stripe are now sharing their experiences, and though not all of them have a documented disability, I am happy that at least their voices are now being heard. These books at least give credibility to the idea that men can be successful parents too, and provide practical advice to fathers regarding constructive ways to contribute to and build a relationship with children. I can also find solace in the fact that both Michael J. Fox (2002) and Christopher Reeve (1998) share a bit of their parenting wisdom throughout their memoirs –though their children were born prior to the onset of the disabilities that included them in this group of parents.

Michael J. Fox’s (2002) description to his son Sam about “shaky Dad” and the ways that holding Sam’s hand would often calm the symptoms of Parkinson’s was
perhaps the closest I had seen to a real discussion of the relationship between parent and child negotiating a disability. Fox's decision to hold Sam's hand was not aided by anyone else, it was not governed by technology or nurses or support staff – this was a child in direct contact with a father who has a disabling condition. In this way, Fox demonstrated one way to include the reality of his disability into his parenting style without changing the focus of the moment to his disability, but rather allowing readers to focus on the bond that disability helped to create between father and son.

What I found particularly disappointing in each book however, was a lack of practical advice that applied directly to my own situation. For example, in the first book in his series, Brott & Ash (2001, p. 235) remind fathers that it is extremely important to play with a child immediately after birth. They do not, however, suggest ways that this can be accomplished from varying positions (i.e. the seated position required for most wheelchair users). I realize that mass market books like these are designed for general audiences, and that catering to a very specific subset of readers may not be profitable, especially at a time when fatherly representations were just beginning to gain recognition. However, adding a game or two that was specifically designed to be played sitting down would not alienate audience members.

These books also offer the tips and tricks needed to achieve simple goals of early childhood. While my disability forced us to make some inventive choices and create some really interesting solutions that other parents may or may not agree with, these decisions allowed me to realize that each parent is unique. For instance, because neither my wife nor I could drive, using the tried and true method of a car ride for motion in order to get a fussy child to sleep wasn’t possible. Instead, I would hold him on my
lap as I did repeated loops up and down a long hallway in our house. Aside from my own mobility, this was easily the best use of my wheelchair during his early years, because it saved my wife’s back, allowed her to get more sleep, and was the trade-off for the diaper changes that I could not perform.

Regardless of the specific audience for the book, most reference material for parenting and childbirth contain guidance on a series of developmental milestones. These represent the markers that each child achieves as they grow, and tend to set a standard for success. The milestones answer questions like “When will my child walk? When will daily understandable speech develop? When will he or she attend school?” Many texts are organized on a timeline of the child’s life, so that the discussion of school appears within the 24-27 month range, for example. Providing these types of guidelines is certainly useful to parents, as is the advice to “go to the doctor if …” that is also present, but in reading these types of lists, I worry that parents become too fixated on them, and use them as the only measure of success, thereby trapping themselves and their children into a standardized rubric of “acceptable” physical behaviours. To his credit, Brott’s third installment, *Fathering Your Toddler: A Dad’s Guide to the Second and Third Years* (2005, pp. 140-141), suggests ways for fathers to “take pride” as well as “dial back your disappointment” regarding these accomplishments. He writes that, “No matter how well or badly your child does, his successes and failures are not a referendum on your parenting skills.” This comment favours the understanding that although guidelines are useful, they are not set in stone.

Despite the fact that I had found sporadic moments in various memoirs that I could identify with and adapt to my own experience, my search for the representation of
a father who uses a wheelchair continues. As a teacher, my students tell me all the time that print is dead, and that no one reads anymore – and while I have a problem with that, it is at least understandable in terms of the ways we are being led by technology. I'll therefore charge all of us with this single goal: to strive for the equal and adequate representation that we all deserve throughout media. This will solve so many more problems than one father trying to find himself drawn properly on the pages of a book. It will tell everyone that all fathers are meaningful, important, contributing members of society. I make this challenge because regardless of the work that disability scholars and activists have done, the media remains largely entrenched in the stereotypes that Linton articulated nearly 20 years ago. Further evidence was provided later by journalist Charles Riley (2005, p. 1) who noted the following in his survey of the ways that media create and incorporate disability related images:

people with disabilities have not seen the evolution of their public image that their private circumstances have undergone in the aftermath of political and medical progress in the past four decades.

Certainly, some of the recognition and representation that we have sought has been gained in the last 10 years, and I recognize that to focus on a subset of the larger population may distract from the overall goal of more present representation for all persons with disabilities. However, it remains just as likely that by focusing on a subset within a minority group, readers will understand that those who have the ability to be parents and to raise children should be given all of the resources they need to do so
safely and well. This has to include role models that we can look to for concrete guidance.
THE LEARNING CURVE

It is now nine years later, and we have learned a lot since our son’s birth. For one, we learned early on that he is located on the autism spectrum; he has grown up with a speech delay, and we have enrolled him in programmes that will allow him to reach his full potential. We couldn’t be happier with his progress and development.

When I started this journey nine years ago, and I realized that there were voices not heard from in parenting literature, I thought I would be arguing for a flip in the traditional paradigm – the one that demonstrated able-bodied parents raising children with disabilities in favour of one that focused on parents with disabilities raising children without them. Instead, and perhaps more appropriately, I find myself supporting something different from a binary relationship that strictly defines parent and child or able and disabled, because those relationships no longer hold the cultural meaning for me that they once did. To be clear, I am not proposing a relationship that misplaces or re-appropriates the overall role of parenthood – that structure needs to remain intact. Rather, I am suggesting that when disability is involved, the parent-child relationship needs to find its basis more in a trusting partnership where participants can shape experiences together. As a simple example, I needed to teach our son early on that when he and I played catch, the rules would be different: he needed to stand closer to me, and he needed to be ready and willing to retrieve the ball at all times. I’ve found that this simple understanding – that the rules with Dad will be slightly different – has translated wonderfully into other aspects of our son’s relationships, so that he more readily understands that everyone’s needs may be different and unique.
Throughout my time as a father, I've realized some simple truths about fatherhood – about parenthood really. I've realized that being a parent is not about what can be lifted, or moved; it’s not about changing diapers or late-night feedings; it’s about a series of beliefs and ideas that are taught between generations. The things that I remember most about my father are the things that he said, and the behaviours that were engrained -- a simple and elegant respect for the way that the world works, and for the people who inhabit it. These memories have very little to do with who changed diapers when I was younger. What I still hold onto is the idea of a world made better because my father was in it; he taught me things, he supported me. These ideas are not limited to male members of a parenting team. Certainly my mother holds sway there too, and in many things more than my father.

The representation of fathers in parenting literature has been sorely misappropriated for decades. Disabled or not, fathers -- partners - have an important role to play in the process of raising children, and the outdated binaries of past decades should no longer dictate the representational modes present in the work that dominates this field. Dads with disabilities and without, as well as people in relationships that do not fit into narrow categories need not be minimized for the circumstances in which they find themselves. The continued absence of persons with disabilities from parenting literature as anything other than the recipients of care is equally problematic because as Tom Shakespeare (2013, p. 210) pointed out when paraphrasing Brunnberg et al:

I think it is very hard to say that disabled people are desexualized when there is widespread evidence that disabled people are having sex in great numbers. For example, empirical studies
show that young people with disabilities are sexually active in similar ways to people without disabilities.

At this point, I concede the likelihood that existing literature does what Shakespeare argues against above. By desexualizing people with disabilities, it remains easier to see us as constantly needing, constantly reliant on others for our existence, and so does not regard parents with disabilities as viable and productive parents in this way. However, literature that highlights that narrative would solidify a position firmly entrenched in the outdated and problematic medical model of disability and neglects more nuanced and later models which require a greater and more defined context.

All parents are unique because we fill in the parenting narrative of each child with our own experiences and upbringing as well as our own capabilities, based on our own resources. For an example later in life, think about those parents who teach their children how to cook at a young age; now consider a second father who spends time teaching a son or daughter about car repair. Parenting literature would never go so far as to suggest that these two sets of parents are inadequate simply because both did not teach their children both sets of vocational tools, and yet, that same literature does not seem to make room for the possibility that there is a knowledge and understanding given to those with a disability, perhaps to demonstrate that we know what it’s like to be helpless, to need, to be dependent on others for many parts of our existence that go beyond the normal stages.

As a father myself now, that comfy old recliner from home sits in my house. It carries with it the smells and wisdom of three generations of fathers. It is next to a lamp, and is still a comfortable place to read. It’s not my favourite chair, and it is not “Dad’s
chair”, because Dad’s chair in our house has four wheels and spokes. I do however consider it to be a torch passed from father to son as a token of my coming of age as I come into the role of fatherhood.

One of the main arguments that scholars in Disability Studies continue to make is that each story is unique and important. This mentality underscores the need to maintain the individuality of fathers --- of all parents really – within parenting narratives. Parenting literature that is allowed to conflate all fathers into nothing more than a character sketch that is tangential at best to the raising of children, actively engages in silencing the population of fathers with disabilities who work tirelessly to raise their children.

By sharing my own story, readers can see both the similarities that I have with all parents, as well as the unique aspects and colours that my disability adds to the experience of parenting in general. If nothing else, this complicates the narratives of parenting in such a way so that disability scholars can see a new avenue for research and writing, and parents can gain some new insights into what fathers and children can do.
References


*Whose Life is it Anyway?*. 1981. [Film] Directed by John Badham. USA: MGM.
