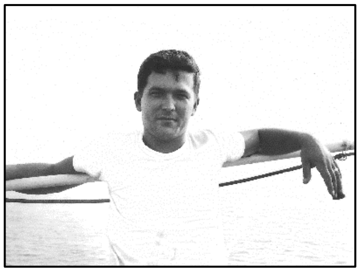
Keep Seeing – Reflections of a Grandfather's Love and Transformation in the Wake of Disability

By Christine Bakter



The last substantive conversation I had with my father before his sudden and unexpected passing was about our office and my role in it. The trip to Arizona I took to see my extended family in October 2021 marked the first time I had seen him since I began my position in the Ombudsman's office – which coincided with the beginning of the COVID-19 public health emergency. While not thrilled that I worked a few hours each morning throughout my visit, Dad was grateful to have me in whatever way I could manage.

Notably, over the course of that week:

- I spoke to the mother of a disabled adult daughter. In the aftermath of Tropical Storm Ida, the two women had been living on the second floor of their moldy and flood damaged home without hot water for a month – in part because she felt there were no acceptable sheltering options that met her daughter's medical and behavioral needs.
- I spoke to another mother who shared her personal experience with the domestic violence system – a system she felt did not understand autism or severe challenging behavior – citing this lack of understanding as the reason her autistic son was living with his father… who was also her assailant.
- We watched the premiere and discussion of the short documentary film "A Voice for Severe Autism."

On the morning I was scheduled to fly back to New Jersey – over cups of coffee before the sun came up – Dad and I did what we always did on these visits. We talked about the stuff that mattered.

After handing me my coffee, he sat down with me and was unusually quiet for a few minutes. I think he had been mulling over the snippets of things he might have heard over the course of the hours I worked each morning. I also shared some general examples of the types of people who contacted us, what they were facing, and how we tried to help. He was disturbed by allegations of abuse and neglect. My descriptions of the pictures we received from families of their loved ones with bumps, lacerations, and bruises – some with blood-spattered walls in the background – were especially unsettling to him.

Breaking the silence, he asked me how I coped with it all. And, in his usual, thinking-out-loud way – he answered his own question before I could respond.

> *"I guess it's your life – I guess once you see the things you've seen – you can't turn your back on people, can you. You help who you can, and I guess if you can't help all of them – at least these people know, **you see them**."*

Dad was, of course, referencing my life with my own autistic son – with its own joys and its own challenges. Over the years, he often told me that he struggled with it all twice: Not only did he worry about his grandson's future – but he worried about the way those challenges affected me – his only daughter. He bore witness to many of the impossibly hard choices I had made – often in crippling isolation – in the twenty years since my son's diagnosis.

Dad was also referencing things he had seen over the course of his 40-year career as a carpenter, tradesman, and business owner. My father had a gift – he made his livelihood making homes look welcoming and beautiful for his customers. However, there was another side to some of the work he had done: work in the homes of families with profoundly autistic children. Memories of these unusual jobs, including the incomprehensible reasons for the scope of work, and the struggles of the families he had served in this way stayed with him – and brought new meaning to him when disability became our reality.

When he left me at the airport later that day – I gave him what would be the last hug we would ever share. I told him I loved him, and he told me he loved me, as we had always come to do when we parted. With a pat on my cheek, he left me this last time with these extra special words – that define the work we do.

> ***"Keep seeing, kid. The world needs you to keep seeing."***

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Six weeks after my father left me with these parting words, he would pass away at home from complications arising from a two-week bout with COVID-19. I was heartbroken and unprepared for the emotions and grief that followed. I wrote the above in those early weeks, trying hard to capture this moment that was so significant and reflective of the person he became after loving and being transformed by his autistic grandson. My father – with all of his working-class rough edges and sometimes impossible, stubborn, stoic pride – became an advocate and ally to our community – because he loved my son and ***he saw***. What he saw with Alex and me began to shape the way he saw the wider world. Before autism became our reality, he didn't always see the issues of our community. For Dad, it had to hit close to home. Over the years, I witnessed how our private struggles transformed him into a public person of compassion, making me understand that there is always hope for evolution and redemption. In short – through the lens of our experience with autism – Dad began to see that the world needed ***people who saw***. He began to act on that understanding and vision in ways both large and small.

Over the years we would have many such talks over coffee in the morning when I visited – or he'd surprise me with a mid-afternoon phone call – and he would share with me the things he observed in the world and how he responded. Often, he'd describe little acts of kindness or service: allowing a mother with a struggling child to step ahead of him in line – deflecting attention away from a child having a meltdown in public –– escorting another mom to her car with a child in distress – telling so many women caring for a disabled child that they were good mothers.

He would share these stories and, almost pleadingly, he'd ask me if he got it right.

Of course, he got it right. He had seen them. And maybe in these private moments of quiet vulnerability with me, he invited me to see him. I began to realize and appreciate that what Dad couldn't necessarily give to me and Alex in the moment and from a distance – he was trying to give to the world at large.

When he died, I considered him a friend – not just to me – but to our larger community. I was privileged to witness how the love a grandchild with a disability shaped him into an advocate and a man of compassion – both at home – and in the larger world. He gave me hope, and his memory and counsel continue to shape what I do, every day.

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