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A Son's Progress, a Father's Confusion: Reflections on Our Asperger's Educational Journey and Literature

David V. Urban

As I begin writing this essay, my memory is fresh from attending a recent on-campus meeting between my older son, Daniel, and a high-ranking human resources officer at my university, where Daniel is now in his sophomore year. The meeting concerned a grievance Daniel had filed several months earlier regarding his belief that, the previous semester, an instructor had mishandled his disability accommodations for his final exam, putting Daniel, who has Asperger syndrome, at a disadvantage. Daniel's grievance might seem petty to some. He still earned a strong grade in the course, but Daniel is seeking admission to an honors program at our university, and his grades are currently just below the level needed for admission, so the difference between an "A-" and an "A" is crucial for his meeting his academic goals. Moreover, Daniel believes he was treated unfairly by his instructor, and I will confess to agreeing with him. Daniel wants me with him at the meeting, but I attend it more as an emotional support and a witness to its happenings than as an advocate. He wants to handle the matter himself.

"Promise me you won't get upset during the meeting, Dad," he tells me before it starts. He remembers that I was angered when I heard his instructor speaking to him in what I felt was a dismissive manner during a Microsoft Teams appointment this past May when Daniel began disputing his grade. The instructor denied Daniel's request that I be able to attend the appointment with him, but because Daniel sat in our living room during the appointment, I allowed myself to overhear a fair bit, and I later told him that I was deeply unimpressed by what I believed was his instructor's condescending attitude.

"I won't get upset," I promise. "I won't say anything stupid."

I sit silently during most of today's on-campus meeting. The human resource officer is very kind and professional. Most of the time he speaks not to me

but to Daniel, who is seated directly across the table from him. It seems that he believes that Daniel is making a legitimate case for himself, but he also clearly communicates the factors that mitigate against Daniel's grievance. As he speaks, I, who am sitting to Daniel's left with a chair's gap between us, alternate my gaze between the officer, my fidgeting hands that rest on the table, and Daniel. I am very nervous about the outcome. I very much want Daniel to gain admission to the honors program. I wonder if I've pushed him too hard in his studies, but I also recognize that Daniel filed the grievance on his own initiative. I cannot imagine having done such a thing in my first year of college.

During the meeting, something strikes me: Daniel is giving the officer steady eye contact, nodding respectfully and politely if somewhat stiffly as he listens. It occurs to me that my son has become a responsible young man, a thought simultaneously joyful and painful to me as I consider our journey together these 21 years.

This essay will describe—on some level—Daniel's educational journey as an autistic person, but I suspect that it will chronicle my own education even more: the voyage of self-discovery that my fatherhood to Daniel has brought me through, a journey that has changed my perceptions of myself and much of the literature I teach as an English professor.

Daniel's road to college was circuitous one. Early in life he displayed signs of an intellectual savant. Before he turned two, he knew the names of all the spice jars in our rather extensive spice drawer, and he could pick them and hand them to me or my wife, Adrienne, upon request. He had an amazing memory and learned songs and hymns easily, earning him the affection of our church's worship leader. He could read when he was four, and he seemed to never encounter a book he couldn't read, whatever his actual level of comprehension. At roughly the same time he asked Adrienne and me the following question: "Does one-third, plus half of one-third, equal one-half?" When, after some serious thought, we answered that it did, he responded with mischievous, knowing laughter. "Did you read that somewhere?" I asked. No, he said. It was something he thought of himself while playing with measuring cups. Adrienne and I looked at each other. "Is he a genius?" I nervously whispered.

But Daniel's intelligence was matched by a painful fragility. He tested positive for numerous life-threatening food allergies and needed to be monitored vigilantly in any setting with refreshments. He was easily frustrated, cried easily, and screamed often. And although he got along well with adults, he had a hard time connecting with children his own age. Adrienne and I grew increasingly protective of him, both physically and emotionally. While our longstanding plan to home-school was grounded in the educational, spiritual, and relational advantages we believed homeschooling would afford, I was also thankful that teaching him at home would protect him from the teasing I feared would plague him if he went to school.

I worried about Daniel constantly, and I found myself developing, for better or for worse, my tendencies to push him in ways that would accentuate his remarkable gifts and thus mitigate his various challenges. As an English professor, I naturally focused on his reading abilities. While he was still four, I saw no reason why he shouldn't start reading *The Chronicles of Narnia*. I eagerly approached him with a copy of *The Lion, the Witch, and the Wardrobe*, but Daniel resisted. He was scared of the witch, and he wanted to read *Thomas the Tank Engine* books instead. I was heartbroken that he rejected what I had to offer him, and I even lectured him that he shouldn't be wasting his time on silly books like that. I look back in sadness—and some ashamed bemusement at my own ignorance—as I consider how I disregarded his fragile heart amid my hopes that he would fulfill my own dreams for him. His father's misguided aspirations aside, Daniel generally flourished in his earliest education.

Then, just after his sixth birthday, his condition changed dramatically. He began having roughly thirty meltdowns and panic attacks a day, usually for seemingly trivial matters such as his eating the food on his plate in what he considered to be the wrong order. I especially remember his lying on the kitchen floor, holding his head, and crying, "Mommy—I don't know what is happening to me!" No doubt he was crying to Adrienne instead of me because he knew he'd receive a more comforting response from her. My dreams for Daniel's splendid classical education were rapidly disappearing, and our family shifted into survival mode.

Predictably, Daniel's situation wreaked havoc upon our small family. I felt overwhelmed by the pain and frustration of being unable to help Daniel

“snap out of” his many meltdowns. Adrienne was beside herself with sadness and worry, and caring for Daniel’s problems and researching their causes consumed her attention. Amid it all, our younger son, Gabriel, who was only a year-and-a-half old when Daniel’s equilibrium began to unravel, simply didn’t receive the attention he needed, especially from me. (Looking back years later, I am often struck by how few memories I have of Gabriel when he was very young compared to how many such memories I have of Daniel.) To make matters worse, our family became increasingly isolated. Certain well-meaning but misguided friends, who encouraged us to spank the bad behavior out of Daniel, lost patience with us. And the pastors at our small church which we had helped start—pastors who had previously viewed Daniel favorably because of his striking proficiency in memorizing Bible verses—were clearly growing annoyed with our family.

“Don’t you have a system?” one of the pastors asked incredulously when I told him about our inability to contain Daniel’s meltdowns.

“That’s the problem,” I replied. “He defies all systems.” The fact was, we had no idea what was wrong with Daniel, something that only exacerbated our confusion and sadness.

Our situation at the church became even more problematic when Daniel began publicly having meltdowns after or even during services. It became apparent that the pastors were worried that Daniel was scaring off visitors, and one day they paid our family a visit at our home. Reading a rather predictable Bible passage about having joy and peace in Christ, they exhorted us to “Get out of crisis mode” and start living the joyful Christian life. Eventually I understood the motivation behind the visit.

“Are you telling us you want us to leave the church?” I asked the head pastor.

“Not exactly,” he answered. “I want you to go to a church where you can get some help.”

We took the hint and visited a larger church for the next two weeks. By the end of those two weeks we had been removed from our original church’s email list, and our family’s spiral into isolation and confusion only deepened. If I am honest with myself, I recognize that this sense of isolation and

confusion continues to this day, and that my writing of this essay is on some level an attempt for me to make sense of these ongoing struggles in my own life.

To say the least, Daniel's traditional educational progress slowed considerably during the two years leading up to his eventual diagnosis with Asperger syndrome. Eventually we settled on a modified classical education that encouraged Daniel's reading of various great books but eschewed the study of Latin, something we feared would elicit excessive anxiety. We focused on various therapies, natural supplements, and dietary changes that combined to enable him to bring his panic attacks increasingly under control. With various bumps along the way, Daniel was able to begin his college studies at my university just before his twentieth birthday.

But his diagnosis and my learning of the now well known-characteristics of AS persons also proved to be a new beginning in my own education, one involving a new level of understanding both Daniel and myself. I realized that I was myself "borderline" AS, something that explained my persona as a quirky English professor with an organizationally challenged office. I came to understand why eye contact had always required special effort for me and why it was so hard for me to gather up my belongings at the end of one class and then move into a different classroom. As a yet-untentured professor, I initially wanted to keep Daniel's and my conditions hidden from those at my workplace, fearing that his atypical behavior would be used against me. But after I shared our situation with my department chair, I noticed that news of Daniel's and our family's overwhelming challenges gained for me an unexpected sympathy that had previously been lacking in certain colleagues who found my eccentricities less than endearing. My awareness that my own organizational challenges were related to AS also gave me the courage to discuss my condition honestly with my department chair, something that ensured that at least some of my challenges would be mitigated when I was assured that all of my future back-to-back courses would be held in the same classroom—a minor but incredibly helpful accommodation.

My borderline AS condition also helped me understand better not only the significant similarities between me and Daniel but also our significant differences. For example, my less literalistic thinking has from my earliest days allowed me to use humor through irony and self-deprecation in ways

that have eluded Daniel, whose attempts at humor usually fell flat or came off as simply mocking. (Daniel revealed the pain of this particular challenge when, after I told him that his mocking was inappropriate, he sadly told me, “I’m just trying to be funny like you are, Daddy.”) And although I was given to panic attacks in my youth, my father was always able to calm me down even though our relationship was never as close as mine and Daniel’s is. In the years before Daniel received his diagnosis, my inability to calm him was especially painful for me. Now I better understand the different dynamics involved in our respective conditions, an understanding that somewhat mitigates the combination of failure and rejection I experience when my calming efforts prove ineffectual.

But my learning about Daniel’s AS has also affected me professionally in both predictable and unpredictable ways. Certainly I’ve become far more sensitive to students who experience disability-related challenges of various kinds, and I eventually began telling each class of students early each semester of my own challenges as a borderline AS person. But other points of connection were entirely unexpected. Most memorably, when Daniel—who developed an obsession with Grand Rapids’ minor league hockey team—began to exhibit repetitive perseveration in imitation of his favorite professional hockey player’s slap shot, I realized that his behavior was strangely familiar to me; indeed, it was strikingly similar to that of a character in a play I regularly teach: Gaev, the eccentric uncle in Anton Chekhov’s *The Cherry Orchard*, who regularly rehearses his billiard shots during various unexpected situations. After much textual analysis and extensive research involving both literary and medical sources, I concluded that Gaev does himself have AS.

This “diagnosis” is remarkable in that AS was not a recognized condition until long after the play’s 1904 premier, but my findings are consistent with the precise behavioral depictions that Chekhov, a physician, offers for various characters in his plays and short stories, characters whom literary scholars have noted display traits of different psychological conditions. The result of my analysis of Gaev was my article “Gaev’s Asperger’s Syndrome in Chekhov’s *The Cherry Orchard*: A Diagnosis and a Call for Character Reassessment,” an essay that subsequently influenced Angus Young’s depiction of Gaev in the autumn 2014 production of the play at London’s Young Vic Theatre (personal communication, 2014).

That Daniel's AS could benefit my analysis of literature and even be incorporated into my scholarly writing came as an unexpected delight. But what lingers more continually in my mind are the challenging and indeed convicting connections between my relationship with Daniel, his AS, and the literature I teach. For some years now, as I have thought about how the discouragement and self-doubt that Daniel faces has been exacerbated by my own criticism of and exasperation with him, I think upon Mama from Lorraine Hansberry's *A Raisin in the Sun*. When her adult son, Walter Lee, is exhibiting his most regrettably irresponsible behavior, Mama unexpectedly shifts away from her earlier criticism of his aspirations to own a liquor store and instead reflects upon her own shortcomings. "I've helped do it to you, haven't I son?" she admits to him. She continues: "Walter I been wrong . . . Listen to me, now. I say I been wrong, son. That I been doing to you what the rest of the world been doing to you" (1994, 2.2, p. 106). I can still remember several years ago when I all but quoted these words directly to Daniel and how much it meant to him that I admitted how I'd hurt him with my words of disappointment. It's an apology I've had to repeat many times since, and teaching this play on an annual basis has reminded me of my need to keep short accounts with Daniel.

Another play that has plagued my conscience is Shakespeare's *King Lear*, particularly regarding the title character's obvious and destructive favoritism of his youngest daughter, Cordelia, over his older daughters, Goneril and Regan. Early in the play, however, he banishes Cordelia for failing to flatter him, after which Goneril and Regan discuss Lear's longstanding disposition. Regan comments that their father "hath ever but slenderly known himself" (2014, 1.1 296-97). Although Lear eventually reconciles with the ever-gracious Cordelia, he never comes to peace with his embittered older daughters, each of whom dies a tragic death before Lear himself dies. In my relationships with Daniel and his younger brother, Gabriel, I am regularly faced with how much easier it is for me to relate to Daniel, with whom I share autistic characteristics and various intellectual and recreational interests. Gabriel often suggests that I favor Daniel, and my impulse to deny such an idea speaks, I fear, to my own slender self-knowledge. The combination of my time-consuming efforts to aid Daniel and the extra effort required to reach out to a younger son who is less like me, one whose interests are often far different from my own, one who is less receptive to receiving what I can most conveniently offer him, has brought about a certain degree of estrangement

with Gabriel. What is most painful is to recognize how my proactivity to aid Daniel's development has not been matched with an equal amount of intentionality toward Gabriel. I have had to face the fact that I have taken him for granted and that I took too long to recognize that his needs are just as great as are Daniel's. My slender self-awareness regarding my neglect of Gabriel is something I need to consciously strive against lest I simply fall back into the comparative ease of established ways of relating.

As I reflect on all these matters, including Daniel's ongoing journey as a college student, I am plagued constantly by the words of Prospero, the deposed Duke of Milan and powerful magician in Shakespeare's *The Tempest*, who tells his teenaged daughter, Miranda, "I have done nothing but in care of thee" (2014, 1.2 16). His words on one level are deeply touching, for they speak to the unrelenting dedication he has shown Miranda in the twelve years since they were exiled from Milan and landed upon a remote and largely uninhabited Mediterranean island. But the degree to which his words to Miranda are fully truthful and genuinely trustworthy is challenged by readers who protest that his protective and controlling behavior toward Miranda is more motivated by selfishness than love. Such readers also suggest that in his commitment to Miranda, he also hurts other people whose concerns he subordinates to his agenda for Miranda's wellbeing.

As I reflect upon the decisions I have made regarding Daniel's education, I am forced to ask various questions of myself. Was I wrong to hold Daniel back an extra year from graduating high school because of the delays in his education connected to his AS challenges? Was I wrong to tell him that I wouldn't pay for dormitory living—whatever it was during the height of COVID-19 restrictions—when he could easily commute with me? Have I been wrong to be so available to him throughout his time at the university? Am I wrong to spend so much time with him on campus, preparing for classes and grading while he studies in the same room? Should I force him to be more independent? Should I allow such independence in part to reverse the disproportioned attention I have given Daniel over Gabriel? Perhaps I have grown so close to Daniel that I can't bear to see him move out. Perhaps I am so worried about his emotional fragility that I can't bear the thought of his facing heartbreak. Perhaps I am concerned about Daniel being lonely at college, knowing how difficult it is for him, like many AS persons, to make close friends. Perhaps I am too plagued by stories of colleagues at other

schools who have told me how their AS children simply weren't able to graduate college because their challenges were too great. Perhaps I think too much about my AS student from a decade ago whose superior intelligence was overshadowed by his social difficulties and who, I was told, was ridiculed in his dormitory.

And certainly another factor—Daniel's first-semester meltdown during his physics final exam—influences my investment in Daniel's collegiate progress. Particularly haunting is the fact that I could have prevented this painful incident altogether. I only realized too late that I should have been proactive enough to suggest that he request that his final exams be spaced out in a more advantageous way, something to which our school's disability coordinator and his kindly physics professor would have readily agreed. In retrospect, it would have been so easy to pursue such an accommodation, but I didn't have the experience or the imagination to encourage Daniel to make that request. But in any event, that traumatic experience has motivated me even more to be available to Daniel to counsel him regarding the various challenges that face him. Have I overdone it at times? I'm sure I have, but as I ponder my colleague Kevin Timpe's article in this special issue, and its discussion of his and his wife's herculean efforts to ensure an appropriate education for their disabled son, perhaps I ought not fault myself for wanting Daniel to take full advantage of the resources available to him, even if at times I myself am his prime resource. Nonetheless, I cannot deny that my commitment to Daniel's education has come at the cost of my commitments to other crucial relationships. I know that I still haven't found the proper balance.

As I conclude this essay, I do so in the wake of Daniel's having been granted the appeal I mention in my opening paragraph. He was allowed to retake a portion of the exam, and he did so using the special testing location afforded to disabled students, a location unavailable during the 2020-21 academic year. He studied diligently for the test, and he tells me he believes he did well. I try not to be nervous as he awaits his final grade, but he seems more concerned about making sure that he and that course's instructor are reconciled with each other; he worries that his appeal caused the instructor professional embarrassment and personal unrest. I am humbled by his character, and it inspires me to mend the relationships I've neglected amid my confused and imperfect dedication to Daniel's education.

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References

- Attwood, A. (2006). *The complete guide to Asperger's syndrome*. Jessica Kingsley Publishers.
- Gillberg, C. (2002). *A guide to Asperger syndrome*. Cambridge University Press.
- Hansberry, L. (1994). *A Raisin in the sun*. 1959. New York: Vintage.
- Shakespeare, W., Bevington, D. *The Necessary Shakespeare*, 4th ed. (20014). Pearson.
- Urban, D.V. (January 2020). Growing personally and professionally from my son's Asperger's syndrome." *Autism Support of West Shore Newsletter* 2.1: 1-2.
- Urban, D.V. (2013). Gaev's Asperger's Syndrome in Chekhov's *The Cherry Orchard*: A diagnosis and a call for character reassessment." *Australian Slavonic and East European Studies* 27: 35-60.
- Urban, D. (December 2020). Reflections on our college experience. *Autism Support of West Shore Newsletter* 2.13: 9-10.
- Urban, D. V. (2021). Slender self-knowledge and growth through correction: Tragic consequences and redemptive hope in Shakespeare's *King Lear* and Austen's *Pride and Prejudice*." *Renascence: Essays on Values in Literature* 73.2: 127-43.

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