

For the Love of Science?

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IT IS A COLD, cloudy day in mid-January here in New York. Despite the uncomfortably cold temperatures outside, I am sweating under my coat having just rushed to my destination. Still, I am late. Not very late, just 5 minutes, but enough to make me nervous that I have once again made a social blunder that highlights my difficulties navigating unfamiliar places. These people should understand, I tell myself, as I rethink taking off my sunglasses under the fluorescent lights. I look for a room number or a sign. I try to tune out the incessant high-pitched hum of the soda machine, but I do take note, good it takes cards. Should I have a low blood sugar moment, I can avoid a meltdown with a Coke. Plus, I need the last of my cash for the parking structure's smiling attendant. I have it perfectly counted and ready in my pocket so that I can remember to smile back this time. If we run late here, another hour will be added to the fees and my entire plan will be disrupted. I will be too slow to return his greeting, again.

Just as I begin to worry, I will be 10 minutes late, instead of 5 minutes, a college student sporting a bouncy, blonde ponytail arrives at my side with a breathy apology and the appropriate accompanying whoosh of cool air. She was sent to meet me but went back to get my cell number. She is sorry for the confusion, the laboratory is very hard to find. I follow her, attempting to simultaneously unzip my coat, not drop my gloves, and not trip over my own feet as we rush past doors marked with names that have me guessing what classes they teach.

As we turn the corner and enter the laboratory, the temperature changes drastically. The air moves from chilled, lightly scented softness to an oppressively hot, stale mix of dry erase markers and printer ink. Again, an apology is issued about the temperature, something about maintenance, but I have not processed a word she has said since she cheerfully asked me to follow her. No instructions came after, so I tuned her out to avoid bumping into any walls: a humorous but common occurrence in my life.

Just as I begin to work up the energy to ask a question, I am ushered into a smaller room. Crammed inside are a table and two chairs that are eerily similar to my second-grade classroom. On the table are two stacks of papers and two pens. I am told to have a seat, take my coat off, and get comfortable. I am, thankfully, offered water that I quickly

accepted. Ponytail will be back with the water and the interviewer. The word makes me nervous, but I know I am here for all the right reasons. I know the energy I am expending serves a purpose. Or at least I hope this to be true.

Ponytail returns with the interviewer but without the water. I take a deep breath, but I cannot speak fast enough to catch her before, in a whoosh of air, she is gone. I remember the soda machine and tell myself I can wait while simultaneously hoping I can find my way back using its hum as sonar. My attention turns to the interviewer as she is now sitting across from me at the table. She has been shuffling the paperwork, making notes with one of the pens, and must have, at some point, handed me the papers I now find in my hands along with the remaining pen from the table. This is not new. I often find I robotically follow basic instructions while I am thinking about something else entirely: a useful skill when sitting in a statistics class but less so when you are in one-on-one interactions.

I begin to fill out the paperwork with my basic biographical information: name, age, gender, and diagnosis. With the flourish of my scribbled signature, the interview begins. This section is called the interview and is one of many parts to any good research study, I am told by the interviewer. She is also a college student though more formal in her appearance and seemingly further along in her studies. As she discloses the purpose of the study and my requirements as a participant, I am already exhausted. Luckily, the interviewer has promised me that my "little contribution" is just one tiny part of the study and that she and her team will be doing the bulk of the work. I take a deep breath, lick my dry lips, and think of my refrigerator's drink selection.

The questions begin. On this day in mid-January, they are about employment, particularly my employment history. Like many adults on the autism spectrum, it is not pretty. Thirteen jobs in 15 years. There are a variety of reasons for this in my case. I struggled with jobs. I am quickly bored and then distracted by social games that I am still struggling to understand. Most of my issues stem from that fact that I was undiagnosed, living 36 years on this planet unaware of my own neurology and yet expecting success. Fortunately, after years of misdiagnosis, my autism was revealed to me and

helped clear a career path. So much so, that as I sit across from the interviewer, I am missing a day at work.

Still, here I sit, answering these questions and it is like reliving a long nightmare you have finally woken up from. But it is worth it, I tell myself, right? After all, I love science, always have. Science is how we make progress. Science is logical; it has rules. Science is how we find the answers. It helps us understand. And so, it is with this desire to be understood that I have signed up for this and many other studies. I want autistics to be understood. I want us to live fulfilling and successful lives. I want us to have the supports we need accessible to us through the lifespan. I want help for those of us alive now. But it is not enough to want those things, I must be willing to do my part to make them so. Supports need funding. They do not get funding without proof. The proof comes from research. So, the fastest way to make change in the available supports is to start by changing the way, and what, we research. It is with all of this in mind that I participate in days like today. For soon the adults like me, who grew up without a name for our difference, will be spending our time fighting for our geriatric care and then we will be gone. With us will go a wealth of untapped, unarticulated information that could have been collected if we were not so keen on throwing money at genetics and zebra fish. So today, I will relive my trauma for the love of science.

Twenty minutes later, the interviewer begins to shuffle her paperwork again, returning her pen to its place on the table beside mine. She takes a breath as if to begin her concluding instructions. Wait, I say, don't you want to know about now? Don't you want to know why it's different? Or when that happened? Not today, she smiles, that would be an entirely different study. She begins her exit speech and I tune her out. She stands, I stand. She thanks me, then looks unsure as to whether she should reach out to shake my hand. I tell her it is okay to ask autistic persons whether they are comfortable with touch and that handshakes are far preferable to hugs. She smiles a real smile and her shoulders relax down from their position by her ears. Her nerves show me she is still open to learning and that makes it a little easier to begin layering on my winter gear.

Out in the empty hallway, I follow the sound of the soda machine to the exit doors. I stop for the Coke I have been thinking about since I arrived. It is cold and wet, and I can feel some of my discomfort begin to lift. The day is far from over. I still have the 45-minute drive home to tackle, which means highways and traffic. New anxiety replaces the old as I walk back to my car following the visual markers I made for myself on the way there. I turn right at the fountain and check my pocket for my cash by feel. I see the smiling attendant ahead and know the safety of my car is close. I could have taken the train that would have been less stressful, but it would have taken twice as long and cost me twice as much. As it is, the day has cost me more than the 50 dollars I spent from my shrinking checking account. It has cost me my routine, my comfort, and my energy.

As I pull out my car keys, the paper the interviewer gave me on my way out falls to the floor. I look at it closely now that my thoughts are down to a dull roar. It is a thank you note. Inside is the promise for a 25-dollar Amazon gift card

should the "budget be approved" to compensate participants. It also lets me know that if this study ever gets published, my personal information will be kept private. IF. An hour and half in the car, a lost day of work, and a gift card for an "if." I crumple the paper back into my pocket. They should have left it at the thank you rather than let me wonder what they actually spent their budget on. I am certain nobody on the interviewer's team offered up their paycheck to compensate the participants. But this is par for the course. Yet another example of the devaluing invalidation autistic persons face on a daily basis and a fine example of the power struggle with live with. It is no wonder researchers love studying our co-occurring conditions. Depression and anxiety flourish in low self-esteem environments.

I pull out of the parking structure, window down, money out in anticipation. I am ready with my cash and a smile as the attendant opens the gate and tells me to drive safe. As this is not my first research rodeo, he and I have danced this dance before. I like it. The routine of our interaction brings me the stirrings of the comfort I am so desperate for. I turn on my music. A favorite song begins its familiar melody and, with a deep breath out, I can feel my body relax. I will be home soon to the smells, sounds, and creatures that give me solace. I will likely still feel repercussions from today for hours to come. Knowing I will not have the energy for much for the rest of the day, my thoughts wander onto my must-do list for tomorrow.

As I ease into the rhythm of my own thoughts, I merge onto the highway. I begin to ponder the value of a day like today. In my world, this interview has been a sudden storm that will pass but not without doing some damage. For ponytail, the interviewer, and her team, it is one interview out of many, in one study out of a multitude, a blip in the radar of science, yet a sonic boom in the life of an autistic person. It occurs to me that this interaction is one of countless others just like it, in which promises of Amazon currency replace valued interactions with proper compensation. It repeats itself at infinitum across the sciences whose research promises "better supports." I contemplate pursuing the issue by demanding to know what happens to my data, but I fear the response. It is never very reassuring. It never got published. We have started a second study. Or my all-time favorite, do not worry, it is here.

This precarious relationship between autistic persons living on the spectrum and the researchers focused on understanding it needs to change. This scenario must play out differently. Researchers need only look to their knowledge base for small adjustments that they can make to their world to create a more comfortable place for autistic persons to visit. On that winter day in January, a few signs, a sensory friendly environment, and a bottle of water could have changed how much daily allotted energy this joint adventure costs me. Twenty-five dollars toward travel expenses and a parking sticker would have made it an even exchange. A few small adjustments and a little real-life exposure could have made this experience a pleasant one, one an autistic person would venture to repeat. I wonder how often researchers think of the impact their work has on the participants. Not just it is a possible outcome, but also its collection and design. And what about the microlearning moments? Those small

interactions that occur between a researcher and the group they are studying. I wonder about the interviewer and whether she now asks before touching or whether she still does that awkward hand out, hand in gesture. Did she learn from our interaction? Did it change her perspective? Maybe the question is bigger. Maybe the real question is, are researchers stopping to learn from their target groups before they study them or has science lost its humanity? At what point do we demand that the rules change for these encounters? When do we replace costs for gains? It occurs to me that the catalyst for change may very well lie with the autistic persons. Besides being assets to any research team, autistic persons have one vital thing that nobody else has, and it happens to be the one thing that researchers need above all else, the data. It is our information to share. It is our time and energy to spend. In fact, the future of research is in our hands simply because we control the data. It is our future and we must be active participants in our own research, from its inception to its conclusion. We must not be

so free with our data so that researchers will begin to respect our value. We cannot continue to give our data away at such great cost for such little gain. We must require better and it all begins here. Before you participate in the next study, for the love of science, ask yourself, how many Amazon dollars is my data worth?

Author Disclosure Statement

No competing financial interests exist.

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