### Inclusion

### My Experience in Information Dissemination -- Manuscript Draft--

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1

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INFORMATION DISSEMINATION

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1

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#### Abstract

My name is Drew Milne and this paper describes my experiences working to disseminate research findings. I've always been fascinated with the ways people communicate, and I wanted my work to contribute to helping people. In this article, I describe my pathway to becoming an information dissemination specialist. I also share important lessons I learned as I built my career. Finally, I offer suggestions on how researchers can support more self-advocates to work as information dissemination specialists. If we can all be more willing to listen closely to people who may not express themselves in exactly the same way as we do, we can all experience the benefits of new ideas we may have never heard before.

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#### **My Experience in Information Dissemination**

My name is Drew Milne. I am a communication specialist on the Communications Team at the Sonoran Center for Excellence in Disabilities at the University of Arizona. As a communication specialist, I help my organization deliver our knowledge and resources to the people that need it most. This could be other organizations or people in the wider community.

My background may be somewhat unique for someone in my position. To some, the idea of an autistic person working in communications is contradictory, even impossible. One of the key features of autism is, after all, a way of interpreting social cues that differs from the neurotypical population. While I may express myself in a different style from my peers, I believe my journey has given me unique insight into the ways people communicate.

#### **Choosing a Career in Communications**

I've always been fascinated with the ways people communicate: language, media, art, etc. It is through communication that we try to make sense of the world around us and connect to others. We communicate to express our needs, wants, hopes, dreams, fears, anxieties, ideas, memories, perspectives, stories - everything that can possibly be expressed in words or otherwise. I knew since I was young that I wanted to work in the communication field - to help bring people together and share these precious parts of our lives: my own or someone else's.

I also wanted my work to have meaning, or to contribute in some way to helping people in need. There are many ways to do this, of course, and each has their place in the broader tapestry of communications: investigative writing can shed light on unheard stories or hidden injustices, beautiful creative writing like poetry can lift the spirits of the distressed, and informative nonfiction can share new discoveries in science and medicine that could make peoples' lives easier, to name just a few examples.

As a person with disabilities, including Autism and Attention Deficit Hyperactivity

Disorder (ADHD), communication has an even greater importance in my life. I, and others with

Autism, sometimes feel like we "speak a different language" than the neurotypical world. As a

child, it became clear that something was different about me when I struggled to connect to the

other children at school. Over time, I would "study" them, and with some effort found ways I

could "fit in". I later discovered this is a phenomenon known as "masking", where individuals

with autism or other disabilities learn to hide the traits of that disability.

After entering the disability advocacy field, I don't find it necessary to mask as much as I did when I was younger. However, I still face challenges sometimes. When I find it difficult to navigate the social cues of communicating in person, I find that the written word allows me to collect my thoughts and present them in a clear and concise way. In this way, I can cross the "language barrier" that separates us, both for myself and on behalf of others with similar challenges. Of course, every person with Autism, just like every person in general, is unique. Communication that works for me may not necessarily be understandable to everyone else like me, or vice-versa.

#### Pathway to Becoming a Communication and Information Dissemination Specialist

It was never a straightforward path becoming a communication specialist. My desire to explore communications began in high school. I remember reading the great literary works of Fitzgerald, Steinbeck, Shelley, Poe, and others. These stories provided me an escape from the often overwhelming world. The richly constructed characters, with their own deeply held motivations and personalities, helped me understand how people relate to one another when it all seemed so confusing from my perspective.

At the same time, I began to seek out more nonfiction, especially journalism. I became engrossed in the idea that billions of stories are unfolding all around us, every day, not just in the pages of books but out in the real world. Intrepid journalists can seek out these stories, and help their subjects be heard in a way they otherwise would not, an idea that brought me comfort when my own voice felt so small.

After obtaining my undergraduate degree in English with an emphasis in Creative Writing, I worked at some odd jobs for a few years while obtaining freelance writing gigs wherever I could. I wrote for local magazines and online publications. Eventually, I was referred to the Sonoran Center for Excellence in Disabilities and was told there was an opening for a communication specialist.

At the Sonoran Center, I found out that there is a lot of information about resources, services, breakthrough research, etc, that could be extremely useful to people in need. However, oftentimes this information is missed by the very people who need it most because it is presented in a way that they can't understand. In addition to a simple language barrier (i.e. information distributed in English being missed by non-English speaking communities), the language of academia is often incomprehensible to much of the population, let alone people with intellectual or developmental disabilities, or those who have other reading difficulties like dyslexia.

There is a huge opening for the use of plain, accessible language - in the healthcare field and others. "Accessible language" refers to clear words and phrases that are easily understood by most people. I discovered that I can use my knowledge of communications to directly help people. I can improve people's lives by helping them access the information and resources that were unavailable to them before. One of the ways I do this is by reviewing documents sent out by the Sonoran Center and make edits so that the language is accessible for most people. I have

also been working with the web design team to make sure our website is easily accessible by people with disabilities. By doing this, more people can be connected to the Sonoran Center and the services we provide. I find this to be a wonderful opportunity to leverage my passion for the written word to make a real difference in the world.

## Helpful Strategies to Overcome Challenges with Starting a Career in Communications and Information Dissemination

In the world of communications, notoriety is everything. Meaning, the more your name is worth, the more likely it is people will be willing to pay for it. Of course, this leads to the common problem of "Can't get a job without experience, can't get experience without a job." The biggest hurdle when it comes to communication and information dissemination is the first one: getting your foot in the door. I did my best to make things easier by creating a portfolio that showcased my work in a variety of different styles. This included pieces from college and articles I'd done as a freelancer. Some people, especially those with intellectual and developmental disabilities, may have a difficult time keeping track of their past works, so any assistance with organizing one's work would be very helpful to those trying to get into the field. Job Coaches and Vocational Rehabilitation Counselors can be helpful in this regard, as well as task management software.

As I entered into the world of communications and information dissemination, I also realized that every organization has its own 'voice' that it works to cultivate. A creative writing magazine will have a different voice than a disability nonprofit, for example. This depends on many factors, such as the audience that an organization is attempting to reach, the image and character the organization is building, etc. It is helpful, in the interview stage and the onboarding

phase of the job, to discuss with the potential employee what type of voice you are aiming for: professional, conversational, casual, sensational, informative, etc.

Other accommodations (things that people need to do their work) that I found helpful included ongoing feedback and discussion with my employers, reminders about deadlines, work from home opportunities, and sensory-sensitive work environments (like the use of noise-cancelling headphones for example). Many of my challenges revolved around organization, executive dysfunction, and sensory issues; which is relatively common for people with ADHD and/or autism, and could be accommodated fairly easily. Other employees, however, may need more hands-on assistance involving a dedicated mentor. The easiest way to gauge an individual's support needs is to ask, both during the hiring process and in an ongoing dialogue on the job, as needs may change over time. Not only does this help employees get the resources they need to do their jobs, but it helps them feel included and respected.

For an inclusive research team, it could be helpful to provide members of the team with I/DD with advance notice of what will be discussed in team meetings. Notes on what was discussed in the meetings could be sent out afterwords also, to help them remember what was said. Other accommodations could include step-by-step instructions for their part of the project, or frequent check-ins with a mentor or peer.

#### **Examples of Projects**

Since joining the Sonoran Center team in Autumn of 2021, I have written dozens of articles for the Sonoran Center website. These articles have covered a wide range of subjects, including covering Sonoran Center events, announcing new grants and projects, and interviewing past and current Center employees and affiliates. These articles have helped drive traffic to the

Sonoran Center's website, and informed potential partners and the community at large about the Center and its mission.

I also played a major role in creating our application for the Self Advocates Becoming Empowered (SABE) - Self Advocacy Resource and Technical Assistance Center (SARTAC)

Accessible Communications Project, a series of training sessions which will help the Sonoran Center and its partners to become leaders in the field of accessible communications. Not only that, but the project will help expand the knowledge and use of accessible communications (like Plain Language) throughout the state. The application was accepted. I am currently the leader of the State Team for Arizona, which has members from the Sonoran Center for Excellence in Disabilities, the Arizona Department of Economic Security, DiverseAbility Inc., and the Southwest Institute for Families and Children.

# Ways to Support More Self-Advocates to be Communication and Information Dissemination Specialists

From my perspective, the single best way to encourage more self-advocates to enter the field of information dissemination is by providing more opportunities to those at the beginning of their careers. By giving more up-and-coming writers and communication specialists an opportunity to prove themselves, the field as a whole will flourish thanks to a wider diversity of voices.

In addition, increasing the use of plain language overall would help people with intellectual and developmental disabilities enter the field. With more people with I/DD in the field, who are already skilled in the use of plain language, more communications would be accessible. This process could create a feedback loop with the overall result being that more people are able to find and utilize the resources they need.

With all this being said, it's worth pointing out that real inclusion should mean having the input from people with intellectual and developmental disabilities at every stage of the process. This goes beyond mere tokenism; this means incorporating the feedback of people with I/DD in the planning, writing, editing, and publishing of materials. This can look like asking colleagues with I/DD what is important to them and what they'd like to write about, brainstorming ideas for articles or projects with them, and allowing them to review materials before publication.

#### Conclusion

Ultimately, I am grateful for the opportunity to use my skills to help people access valuable information and resources. The world we live in is a complicated one, and it can all be overwhelming to someone who communicates differently from the majority of people. If we can all be more willing to listen closely to people who may not express themselves in exactly the same way as we do, we can all experience the benefits of new ideas we may have never heard before.