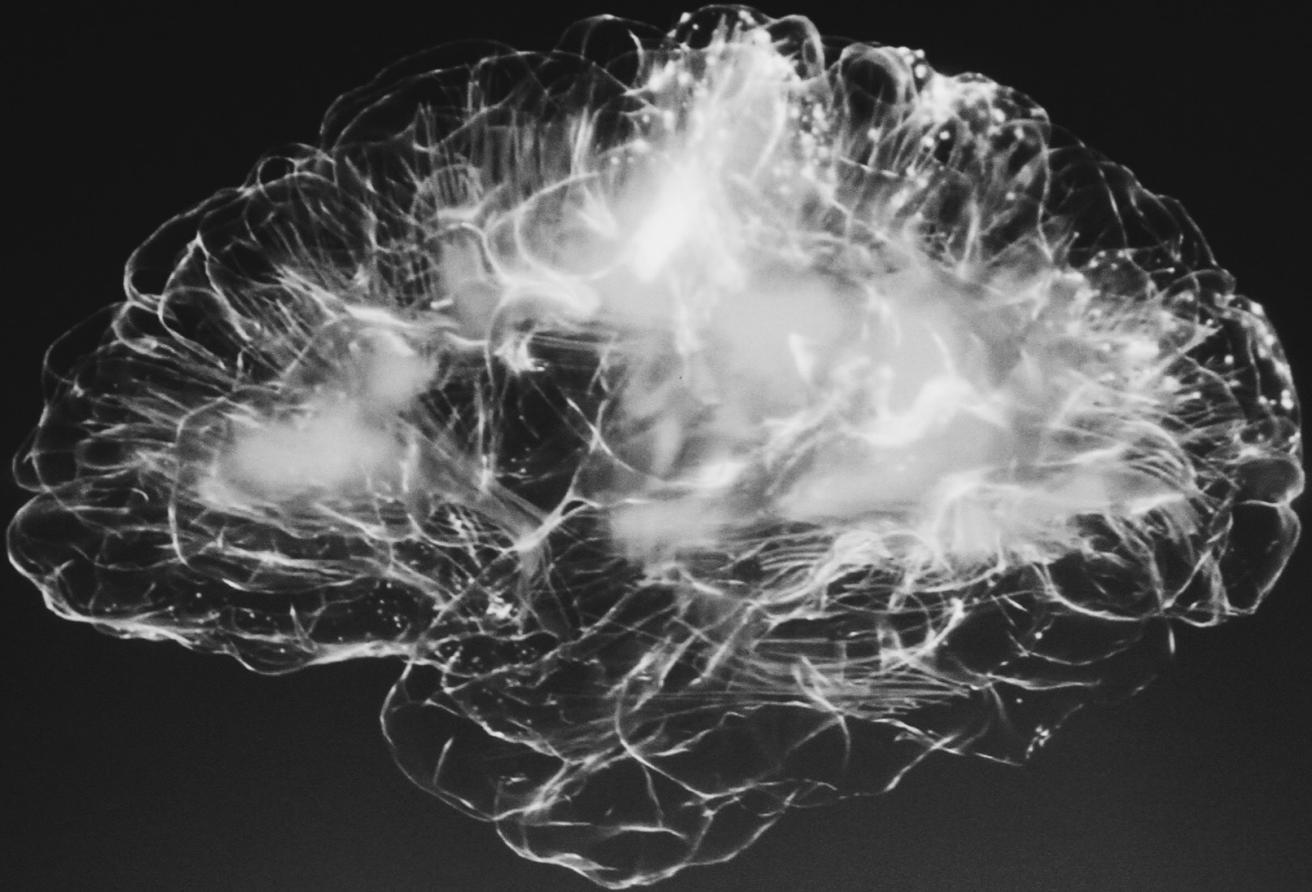




Stanford
MEDICINE | Radiology

Diversity Newsletter

Vol. 2, Issue 6



“We should celebrate neurodiversity – the world would be poorer and life duller if we were all the same.”

– Neil Milliken

Neurodiversity

Dear colleagues,

Our July newsletter is dedicated to “neurodiversity”. Neurodiversity describes the concept that neurological differences are recognized and respected as natural variations of human beings rather than deficiencies. These neurological differences can include those labeled with Dyslexia, Attention Deficit Hyperactivity Disorder, Autistic Spectrum, Tourette Syndrome, and many others. Neurodiversity represents the idea that people with neurocognitive variants do not need to be cured; they need to be accommodated to realize their unique talents. An example is shown in the video below.

We all have a 2 million year old brain. Since the emergence of the homo genus, our ancestors migrated around the globe and inhabited many different environments. As a result, the human brain tripled in size and formed a variety of unique new neurological traits. This was not always an evolutionary advantage. The large brain consumes about 20% of our entire metabolism. However, the variety of newly developed neurocognitive abilities enabled humans to survive in vastly different environments and optimized their social competition for scarce resources.

Our newsletter will provide insights on different aspects of neurodiversity: We will learn about challenges and possibilities of unconventional brain functions and thought patterns. We will also learn that we can choose what things mean and what to focus on. Perhaps the most interesting people are the ones that see the world a little differently. I would like to thank our authors for sharing their inspiring experiences! And I thank you for joining the journey!

Heike E. Daldrup-Link, M.D, Ph.D.
Associate Chair for Diversity
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KODI LEE CREATES A HISTORICAL MUSIC MOMENT AT AMERICA'S GOT TALENT 2019

Kodi Lee, a 22 year old autistic and blind young man, impressed the judges of America's Got Talent with an outstanding and heartwarming performance. Kodi received a standing ovation from the audience and a roaring applause from all four judges.

<https://www.youtube.com/watch?v=pDPdRYF7hTQ>



Embracing Individual Differences

As a female and first-generation Guyanese-Canadian, diversity is a topic close to my heart.

Workplace diversity encourages broad ranges of talents and perspectives, and can improve both company productivity and morale. I feel incredibly lucky to have been immersed in environments that promoted diversity from a young age. However, I realize that for many others in the medical community and elsewhere, this is not a shared experience. As a current member of the Stanford University and Organization for Human Brain Mapping (OHBM) communities, it is highly encouraging to see diversity committees dedicated to improving the experiences of under-represented groups and minorities. Themes such as “Celebrating Diversity” have been prominent at previous OHBM conferences and happily embraced by my colleagues and I (as displayed on our name badges), among thousands of other meeting attendees.



While diversity is often discussed in terms of ethnicity, gender, religion, and age, it is important to also support the concept of neurodiversity. Neurodiversity embraces neurological differences as part of normal variations in humans. It is a concept that challenges views that assign “disorder” labels to individuals who have received diagnoses such as autism or dyslexia, and helps to break down societal barriers that prevent their inclusion. In recent years, improved awareness about neurodiverse workforces has inspired a number of large corporations to foster environments that better support different perspectives and ways of thinking. This movement has proved to be beneficial for all parties involved.

In general, diversity is a requisite for growth and innovation. As explained by entrepreneur Nick Walker in a recent Fast Company article (Nerenberg, 2017), “In any given sphere of society, we only get the benefit of the contributions of those individuals who are empowered to participate.”

Danielle DeSouza, PhD

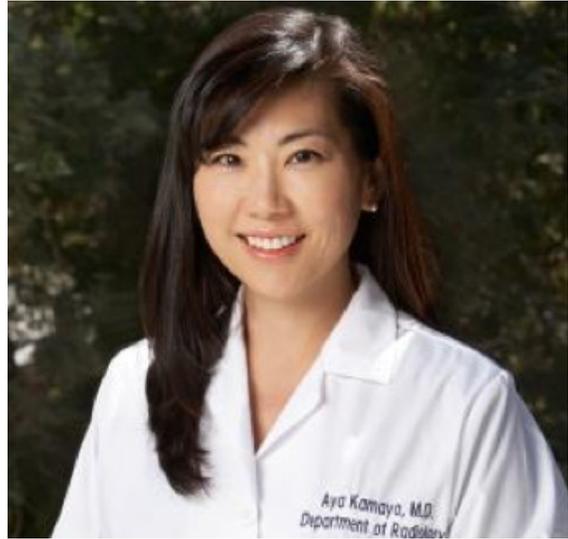
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Are You Neuro-diverse?

Diversity and neurodiversity is all around us and recently I have come to realize that I am quite neurodiverse. For instance, how would you answer the following questions?

1. Would you rather be a world class athlete or a world class mathlete?
2. Would you prefer to spend the day at a football game and tailgate or would you rather spend the day skiing?
3. Would you prefer to watch an episode of Game of Thrones or play the piano for an hour?
4. Do you prefer to spend the day at the pool or go surfing in the ocean?

I don't want to give you my answers because that would be embarrassing but suffice it to say, I answered exactly the opposite of my husband in each of these questions and yet we get along very well!



Aya Kamaya, MD

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Neurodiversity at Home



Oldest son in basic training

As I understand the neurodiversity movement, it proposes that we start to recognize the enormous gifts that the neurodiverse population offers and stop focusing so much on how different they are. I appreciate the overall concept. I have 5 children, 2 of which are part of the neuro-diverse population, one with ADHD Inattentive Type and one with Autism Spectrum Disorder Level 1 (more commonly known as Asperger's Syndrome).

The current theory with treatment of these disabilities is to diagnosis as early as possible and get the child into an intervention that trains them to act and behave as a "normal" child. The problem with this, as I've found, is that it's hard (extremely hard) to get an early diagnosis for children with comparatively mild symptoms. Once the diagnosis is received, there is no plan of action on what to do from there. There is no case-manager, no guidance. Parents are left to manage treatments and therapies based on the initial diagnosis.

My oldest son was not diagnosed with ADHD-Inattentive Type until 8th grade, which meant that he was already struggling with schoolwork and with behavior at both home and school. It meant that he already had an extremely low self-esteem and believed himself to be lesser than his peers. Innately, he knew that he was different and not able to perform in the same way as other boys his age, he just didn't know why. My son went on to struggle throughout high school. During his Junior year, with a GPA of 1.2%, he enrolled himself in a boarding-type military charter school where they focused on the child as a whole. The program (run in part by the California National Guard) used the military structure to help him learn to manage emotion and change, while providing one-on-one education until he mastered a skill. My son graduated from this military charter high school 6 months early and with a 3.5 GPA. The difference in his personality, self-esteem, and general well-being was remarkable. He was able, in this new educational format, to truly shine – to show his unique potential and incredible intelligence.

This same child is now an adult and has continued to struggle in a world built around expectations that are more reasonably attained by a neurotypical individual. He joined the US Army at age 18 and excelled through bootcamp and combat training –earning an expert marksman rank and a "Hero of the Battle" award for meritorious performance, which recounted him carrying a 'casualty' on his back 3000 meters to the ambulance exchange checkpoint. After training was complete and he was expected to perform his day-to-day job as a non-deployed soldier, he began to fall behind. ADHD causes a lack in the executive function skillset. So, showing up to formation each day at a specific time, clean shaven, and behaving as a neurotypical individual throughout the day eventually became the end of his lifelong dream of being a United States Army Ranger. He was less-than-honorably discharged 18 months after joining for conduct unbecoming a soldier- A stark contrast to the highly recognized soldier at the beginning of the military contract. The Army is a whole different beast, however, I imagine he will continue to struggle in the workforce until the neurodiverse individual becomes welcomed and their struggles with executive function and behavioral differences are accepted as part of that individual.

My middle son was diagnosed with Autism in the 3rd grade. I knew, from my experience with my older son (there are 10 years between the two boys), that this child thought differently than my other children. Once he got into school, it was apparent that he was not learning in the same way as his peers. It took me 4 years, visits to multiple doctors and many specialists to get a diagnosis. The problem was (as it was with my older son) that his symptoms were relatively mild. Many doctors just interviewed us for 30 minutes to an hour and sent us on our way with a diagnosis of anxiety or depression. Those were unacceptable diagnoses for me. I knew my son. He was not depressed and did not have anxiety. Sure, he feared certain things or places – but not all. I finally found someone in a different state, about an hour

Neurodiversity at Home

drive from where we lived that would do a full educational/ psychological exam. It lasted 2 visits, approximately 2 hours per visit. The diagnosis came through as on the Autism Spectrum -mildly, but enough to affect the way he learns, behaves, and interacts with peers.

The current recommended treatment for ASD is occupational therapy, applied behavioral therapy, and cognitive behavioral therapy. I've found the process to manage an ASD child's therapies is confusing at the least and typically falls on the parent. I have no medical education, I don't even know what those different types of therapy are, let alone where to find those type of providers. And each therapy is regarded as a specialist, which involves a higher co-pay.

My son, now 12, has been in occupational therapy for almost 5 years and just last year graduated from speech therapy after 8 years. The problem I see is that, despite those years of interventions, he is still suffering in school, still falling behind, still quite aware that he thinks and communicates in a different way than his peers.

So, have all those years of occupational therapy really helped him? Yes, he can now maintain eye contact during most conversations, but is that really something that he needed? Typically, these individuals are avoiding eye contact so that they can hear and think without the distraction and stress of looking into someone's eyes. If we just trained my son to look into people's eyes because it's what we neurotypicals expect, what does that do to his state of mind during a conversation? It makes him more prone to stress overload and eventual meltdown.

If our current way of treatment works, then we would expect, after the child has been in therapy, that symptoms would recede or become more manageable. However, I find that the symptoms persist. Especially during emotionally elevated periods, when you need those interventions and coping skills to work the most. For example, when my 12 year old son on the spectrum, who is now taller than me and almost out-weighs me, has a meltdown, he becomes irate, he cannot hear what people are saying anymore, he throws things, he screams, he shakes, he hits himself, he throws himself into walls. I cannot intervene safely in most cases, just due to his size. This is a time where I need those interventions to kick in, to help him cope. Often, they don't.

What has worked the best for us is knowing when he's getting to the point of meltdown. When we recognize that he's becoming overloaded, we can still talk to him and let him know that he's being heard. I usually try to get him into a quiet room, and wrap him up in a weighted blanket. Then, he can usually modulate his emotions in that quiet space within about 10 minutes or so. This type of prevention could be invaluable to these individuals in school or in the workplace. What if teachers, or co-workers, knew what to look for as signs of a meltdown and we could help the individual get to a safe place to work through the emotions that are crushing in on them? What if, instead of trying to force them to act like we do, we make it acceptable for them to act like they do?

One big hurdle to face in the neurodiversity movement is our educational system. It is not setup to teach those that learn differently and is definitely not able to cope with alternative behaviors. We need a school system that will identify struggles (in any child) early and assign a teacher to work with that child until he/she catches up to the class. This as-



Middle son



Middle son in his cocoon swing

Neurodiversity at Home

signed party needs to be fluent in several different teaching styles, so that the child will be able to learn and understand in a way that makes sense to them. We need the schools (and workplaces for adults) to offer sensory rooms, places with minimal noise, calming colors, and no smells, so that the neurodiverse person has a place to calm down and try to quell the ever-growing sensory overload that is almost inevitable in a day full of people, and learning, and sounds, and smells, and touches, and expectations. All of which are so interruptive to a person with a neurodiversity.

I can talk a lot about what made my boys suffer in school and during their lives thus far, but let's talk for a moment about what makes them two of my favorite people. First, even in an educational system designed to work with a different type of brain, these two are passing through each grade (maybe with low scores but still passing). It's akin to being in a class taught in a language you only partially understand. Second, their memories of facts are impeccable as is their knowledge of subject matter that is interesting to them. My oldest son is very interested in space exploration and military strategy. He could out-teach any history text book on his subject knowledge alone. Third- and contrary to common misconceptions -they are both incredibly empathetic. They do not always know what to say or how to say it, but they love intensely and unconditionally. This is one of many reasons that emotional overload happens so often and so quickly. Everything you say matters to them. They hear it, they sense it, they feel it deeply. Sometimes it may seem that they are ignoring you or that your comment doesn't matter, but they heard every single word you said, and they can understand some things that you only thought. Finally, both are remarkable at video games. Designing games, playing games, and winning games.

They are both successful in the areas that make sense to them. They both suffer in the areas where society is trying to make them fit into the neurotypical mold. Imagine a world where they could learn in a way that fit their needs, how successful would they feel – how confident? If we met all neurodiverse individuals with an educational experience tailored to their needs and a society that understood that they need to communicate in a different way, this population would be unstoppable.

Amy Thomas

Web Designer
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The Stanford Neurodiversity Project: Empowering the Neurodiverse Population

In April 2017, several Stanford faculty and I attended the second Annual Autism at Work Summit at SAP. We heard stories after stories from SAP employees with autism about how their jobs have changed their lives. Due to the intrinsic challenges in social interactions, individuals with autism have difficulties maneuvering the typical job search and interview processes. In fact, over 80% of adults with autism are unemployed or under-employed. After we returned to Stanford, a few of us got together and started talking about how we could help with hiring individuals with autism to work at Stanford.

In Fall 2017, I founded the Special Interest Group for Neurodiversity (SIG-Neurodiversity). We define neurodiversity as a concept that regards individuals with differences in brain function and behavioral traits as part of normal variation in the human population. We started inviting speakers to come to our monthly meetings and talk about topics on neurodiversity. In our first meeting in November 2017, we thought we would have only a handful of us, but we had 23 attendees in the first meeting and built a rapidly growing community from there. We have been fortunate to be able to invite very good speakers. The topics usually relate to employment, education, or mental health for neurodiverse individuals. Soon after the first couple of meetings, companies around Stanford started requesting for opportunities to participate in our monthly meetings as well.



In April 2018, Dr. Laura Roberts, Chair of Department of Psychiatry and Behavioral Sciences, suggested to me that I should escalate my efforts on neurodiversity from a special interest group to a special initiative of the psychiatry department. I was appointed the Director of the Stanford Neurodiversity Project (SNP). There are six major objectives of the SNP:

- Establish a culture that treasures the strengths of neurodiverse individual
- Empower neurodiverse individuals to build their identity and enhance their long-term skills of daily living throughout the lifespan
- Attract talented neurodiverse individuals to study and work at Stanford
- Train talented individuals to serve the neurodiverse population
- Disseminate the Stanford Neurodiversity Model locally, nationally, and internationally
- Maximize the potential of neurodiversity

Over the past year, our project has received tremendous support internally and externally. With a major philanthropic support, we are able to grow the project. Currently, we have three main initiatives:

1. Neurodiversity Awareness and Education Initiative
2. Neurodiversity at Work and Wellness Initiative
3. Neurodiversity Independent Living Skills and Housing Initiative

Within the Neurodiversity Awareness and Education Initiative, we have 5 current activities:

- SIG-Neurodiversity. Since its inception, over 240 individuals have asked us to include them in the SIG-Neurodiversity. Participants call in through videoconference from all over the world.
- Neurodiversity Awareness Program. I have been speaking about the strengths-based model of neurodiversity

The Stanford Neurodiversity Project: Empowering the Neurodiverse Population

and the SNP in various departments at Stanford, locally in the Bay Area, nationally (Nashville, Seattle), and internationally (United Nations, Moscow). I will be one of the keynote speakers at the Autism at Work Summit at Melbourne, Australia later this month.

- Courses on Neurodiversity. I started teaching two courses on neurodiversity. The first course, "Topics in Neurodiversity: Introduction and Advocacy" (PSYC223) was offered in Winter 2019. In addition to behavioral, biological, and social perspectives of neurodiverse conditions, we taught Stanford students on how to work with neurodiverse high-school students. In Spring 2019, I collaborated with Dr. Nicole Ofiesh (Director of the Schwab Learning Center at Stanford) on teaching "Topics in Neurodiversity: Design Thinking Approaches" (PSYC223B). We taught students about design thinking approaches, strengths-based model of neurodiversity, and universal design. In this past quarter, we had a medical student, graduate students from the Graduate School of Business, Graduate School of Education, Department of Sociology, and undergraduate students in Computer Science, Human Biology, and Engineering. The 14 students formulated three projects. The first one was on teaching neurodiverse students how to navigate the process of getting accommodations; the second topic was related to preventive mental health materials that can be taught to residence assistants; the third topic was on performance evaluation for neurodiverse employees. PSYC223B will be offered again in Winter 2020. PSYC223 will be reorganized into three 1-unit courses to be taught in Fall 2019, Winter 2020, and Spring 2020.
- Stanford Neurodiverse Student Support Program (NSSP). The NSSP will be launched in September 2019. This program is a comprehensive program designed to enhance the experience of neurodiverse Stanford students in college by providing support on transitioning to college, social life, independent living, accommodations, learning, and mental health. We have already recruited peer mentors who will serve to facilitate the support on transitioning to college, social life, and independent living. SNP staff members will collaborate with existing groups within Student Affairs to provide support on accommodations, learning, and mental health.
- Neurodiversity seminar series for managers and teams working with neurodiverse employees. This seminar series started in February 2019 after a neurodiverse employee was hired in the School of Medicine. After onboarding of the new neurodiverse employee, I provided support to the manager and team through discussion on best practices for working with neurodiverse individuals.

Our second initiative is the Neurodiversity at Work and Wellness Initiative. Please see below for the two active activities for this initiative:

- Neurodiversity at Work Program. This program provides social skills support, workplace training, short-term coaching as well as customized technical training for neurodiverse participants who would like to be considered for open positions. We provide neurodiversity awareness training, position consultation, neurodiversity best practice training, and on-going support to potential employers at Stanford. We have successfully facilitated the hiring and provided on-going support for one neurodiverse individual in the School of Medicine earlier this year. This work in other departments in the University is in progress.
- Adult Neurodevelopment Clinic. This clinic provides mental health support for neurodiverse students and employees. Services include diagnostic evaluations and on-going treatments such as medication management and psychotherapy.

Our third initiative is the Neurodiversity Independent Living Skills and Housing Initiative. The only currently active program is the Independent Living Skills Program. Our group recently started a formal collaboration with Autism Speaks to co-develop materials for teaching service providers and family members on how to work with neurodiverse individuals.

The SNP has been growing rapidly in the past year. For more up-to-date information about our programs, please visit our website (<http://med.stanford.edu/neurodiversity.html>) or contact us at stanfordneurodiversityproject@stanford.edu.

The Stanford Neurodiversity Project: Empowering the Neurodiverse Population

In this newsletter, I would like to invite you to participate in this movement on neurodiversity. If you like to join SIG-Neurodiversity, please send us an email (see above). Please let us know your interests in neurodiversity. Let us know if neurodiverse individuals you know are looking for employment. Please introduce us to organizations interested in learning more about neurodiversity, and those interested in hiring neurodiverse individuals. Tell us how you want to be involved.

By working together, we can make a difference to the neurodiverse community and beyond.

Lawrence Fung, MD, PhD

Director, [Stanford Neurodiversity Project](#)
Director, Adult Neurodevelopment Clinic
Clinical Assistant Professor
Stanford Medicine | Psychiatry & Behavioral Sciences



The neurodiversity of Alzheimer's: A change in the way you once viewed the world.

Neuronal diversity is what makes people individuals. Everyone's brains process and perceive information differently. Without neurodiversity, life would be less interesting and no doubt fewer scientific breakthroughs would be made. I once read that "Neurodiversity may be every bit as crucial for the human race as biodiversity is for life in general". I truly believe this, but what happens when your cognitive "norm" starts to change?

Growing up, I witnessed my grandmother experience multiple transient ischemic attacks (TIAs) and proceed to go through the progressive stages of Alzheimer's disease. Her first TIA occurred when I was only 1 year old. She continued to live a largely independent life for the next decade. However, by the time I was 11 years old, her dementia worsened and more frequent TIAs occurred. At this stage, my grandmother lived alone. But it became clear, that she would need someone to check in on her more frequently. She moved from the home she raised her family to a local senior housing court. She loved it there, because she could remain mostly independent with nurses checking in daily, mainly for medication purposes. Her two sisters also lived in the court a few doors down and she would go to play bingo and get dinner with them in the social center. However, after a few months, it became clear that her dementia was progressing quickly. Instead of moving her out of the environment she loved, my mother began checking in on her daily, bringing her meals and groceries etc. Finally, after 2 years and multiple incidents of leaving something in the oven or putting the electric kettle on the stove, it was decided that she would move in with us.



My strongest memories are of the time my grandmother lived with us. She was always a very cheerful woman and had an extremely sweet tooth. I remember after another TIA that had resulted in aphasia, she found it difficult and frustrating to communicate what she wanted, although she always found a way to communicate when she wanted bonbons – her favorite treats. She used to convince me to give her extra treats when my mother wasn't looking. She hadn't lost her boldness at this stage; in fact, I don't think she ever did. I can't look at a bonbon without thinking of her even today. She lived with us for 3 years before she needed 24/7 medical care and was transferred to a nursing home a 10 minute drive from our home, so that we could visit her daily. I remember this being a very hard decision for my mother and her battling with it. She had done so much to make sure my grandmother was around her family and living her life to her fullest potential, but the time had come where she couldn't provide the care she needed anymore. This became increasingly more difficult as for the first few months, my grandmother would frequently sit at the front door of the nursing home fully dressed in her coat and hat on. As soon as we arrived, she would be delighted to tell us that she has been waiting for us to bring her home. Quite simply, although we knew it was for the best, it was heartbreaking to leave her there. My grandmother passed away after one year in the nursing home. The last few months were the most difficult. By this time, I was about 18 years old. She was bed-ridden and had completely lost her appetite. She wasn't able to communicate much but could get out a few words about how she went to the disco the night before, mentioning names of people she had met – snippets of what I can only assume were memories. Although I hate to admit it: During these few months, I found it increasingly hard to visit her. I watched her transform from this jolly, full of life woman to skin and bones. This stark contrast always stuck with me.

To me, Alzheimer's disease is also a form of neuro-diversity. Different forms of dementia can result in changes in per-

The neurodiversity of Alzheimer's: A change in the way you once viewed the world.

ception, memory, communication and even vision, creating a different way of looking at and interacting with the world, and indeed a different way than that individual is accustomed to – something I can only imagine is incredibly daunting to the individual experiencing it. Yet, unfortunately, people with neurological diseases are not always treated the same as people with diseases that can be easily seen or related to. A great stigma can come with a diagnosis of Alzheimer's and other forms of dementia. This stigma and fear can often be a deterrent for people to visit their doctor when early signs emerge. This has a substantial knock-on effect to how we diagnose and treat dementia. Less people openly coming to their physician at the early stages of Alzheimer's or even mild cognitive impairment (a stage prior to Alzheimer's, but that will not necessarily progress to Alzheimer's) will ultimately lead to inferior levels of diagnosis and management of this condition. But how can we fix such an incredibly complicated and sensitive issue? It will be difficult, but maybe the first step is to change the way we as a society view dementia. Perhaps we can do this by steps such as openly talking about dementia so as to reduce the fear and stigma surrounding it, putting ourselves in their shoes to better understand changes in behaviors or communication, or simply changing the language we use when talking about dementia (e.g. saying "person living with" rather than "suffering from"). It is also important to see the person first. There is more to a person than their diagnosis and it is possible to live a happy and fulfilled life with dementia. Perhaps as a society we are sometimes too quick to write people off with dementia. Imagine you are told you can't do a specific task. You will likely feel extremely disheartened; your motivation may be reduced, and you may even be incredibly frustrated. Therefore, rather than assuming someone with dementia cannot do something, maybe try supporting them to continue to do the things they can and want to do. In reality, everyone's journey with dementia is different and living well with dementia will mean different things to different people. For some it may mean to continue to work, for others it may mean to be able to maintain their home or a hobby. There is no doubt that dementia brings challenges. However, increased awareness, understanding and support could make the world more dementia-friendly.

My experience with my grandmother also made me mindful of how neurological disorders such as Alzheimer's not only affect the individual but also have profound effects on those who love and care for them. During the years where my grandmother's cognition began to decline, my mother took a 5 year career break to care for her. This was an incredibly selfless act I admire to this day. My mother, with the help of my father, also made sure my grandmother was visited regularly, taken to doctor appointments and generally lived her life to the fullest as long as she could. Therefore, it is not only important to support people with dementia but also their families and careers. Family members do incredible work while often making huge sacrifices and they deserve the support and guidance to continue to do so.

My grandmother's passing coincided with the second year of my undergraduate degree, the year I decided to specialize in neuroscience. I went on to do my PhD in Alzheimer's research and continue to try unravel the mechanisms underlying complex neurological diseases including stroke and Alzheimer's. While we still don't have a "cure" for dementia, maybe we can all do our bit to help create a more accessible and understanding environment for those living with it.

Aisling Chaney, PhD

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“There needs to be a lot more emphasis on what a child can do, instead of what they cannot do.”

– Temple Grandin