

The Future of Neurodiversity

By

Ken Gobbo

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This book first published 2025

Ethics International Press Ltd, UK

British Library Cataloguing in Publication Data

A catalogue record for this book is available from the British Library

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Print Book ISBN: 978-1-80441-306-7

eBook ISBN: 978-1-80441-307-4

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Preface

The idea for this book on the future of neurodiversity came to me while attending a presentation by Nick Walker that was sponsored by Landmark College's Center for Neurodiversity. Like many meetings in a post-COVID world the presentation was offered in a hybrid format. A group of faculty members and undergraduate students were in an auditorium watching Dr. Walker's image projected onto a large screen. I joined the gathering online along with several other participants. During the discussion, participants posed questions and Walker improvised answers based on her knowledge and experience. At one point in the discussion our presenter referred to the work of identity scholar and futurist Ziauddin Sardar. She discussed Sardar's concept of post-normal times, a period during which the old ways of understanding and doing things are expiring and new ways have yet to be developed.

As I thought about this characterization of the world's current, complicated, and somewhat chaotic times, I connected the idea of post-normal times to the environment that surrounds the rapidly growing neurodiversity movement. A movement that seeks a new "normal" is emerging from this post-normal situation. Almost immediately I began to consider questions about this barely thirty-year-old movement, wondering where it is headed in its early maturity, and how some of the issues it currently faces will be resolved.

For over thirty-five years I have worked closely with neurodivergent college students. As a psychology professor I often discussed learning with my students in classrooms, cafeterias, and coffeeshops, during office hours, and into the evenings while on study abroad trips. We talked about the challenges, the psychological and physical issues that almost all young adults wrestle with. Frequently we talked about whether they had learning disabilities, or they just learned differently. Gradually, we became aware of the concept of neurodiversity. We had a word that described the contrast between disability and difference. This book basically grew out of those discussions, and thinking about the many forces that have a direct and indirect bearing upon the develop-

ment of the neurodiversity movement and those who are participating in it, including a growing number of students.

The pressures from political, economic, educational, psychological, and social influences on the neurodiversity movement and its members during these post-normal times are shaping what the lives of neurodivergent individuals will be like in this twenty-first century. Their control as stake holders over that future has been increasing and will likely continue to do so.

As the author of this work on neurodiversity, it is important to take a moment to explain that I am not a neurodivergent person. For that reason, I cannot fully understand what it is like to live the life of a neurodivergent individual with its challenges, benefits, and possibilities. I have spent much of my life working with neurodivergent college students as they confront the obstacles related to their different ways of learning and being in the world. I have always considered myself to be their ally. The work presented in this book is the result of that experience as an educator and researcher in the social sciences. It is based upon and influenced by the day-to-day encounters living and learning with students; as well as studying the available literature that has been produced by both neurotypical and neurodivergent researchers. This book includes several short experiential anecdotes related to theoretical comments that are discussed. As one neurotypical individual I cannot speak for the neurodiversity community. While this work may be seen as a view “from the outside,” I believe it is imperative to include the voices of the growing population of neurodivergent students and professionals in a book about the future of neurodiversity. To this end I have asked neurodivergent students, alumni, and colleagues to comment on the chapters in this book and include their responses and reactions at the end of several of the chapters that follow.

In addition to the limits resulting from point of view, the contents presented here are also limited by the methods of futures studies and the wide range of experiences of individuals within the neurodiversity movement. No one can predict with certainty what the future will be.

There are always unknown variables and uncertain timing that coincide in post-normal times. However, one can imagine preferable futures while examining current trends and controversies. Understanding these trends and opposing sides of controversies may allow for actions that can maximize cooperative, positive outcomes for neurodivergent stakeholders in the future.

Acknowledgements

I am grateful to several people who helped me to produce this book. I would like to thank my colleagues Adam Lalor and Rick Bryck from the Landmark College Institute for Research and Training, as well as my friend Claudia Mastache, for invaluable counsel and advice during the early planning stages of this project.

I would also like to extend my thanks to Jon Bolaski and Darah Kehnemuyi who reviewed individual chapters as they were being written and revised. My heartfelt gratitude is offered to David Carl Bosse for his exceptional work as a copy editor while reviewing the final drafts of this book. Finally, I would like to thank members of the neurodiversity community for writing reactions and commentary to my thoughts on the topics presented here. Their words are included in the pages that follow. They are:

Alexa Darby
Emile Gouws
Melanie Guzman
Eleanor Thomas
Steven Vitt

Introduction

Neurodiversity is a concept that describes the multitude of naturally occurring variations in the human nervous system. It accounts for the wide range of human brains that are the result of an incredibly complex human genome. Neurodiversity supports the idea that not just one sort of brain or mind is normal. It is also an emerging cultural movement that seeks to include individuals who differ from the majority in terms of their neurological makeup, and the resulting ways that they interact with the world around them. Many people who experience dyslexia, ADHD, autism, synesthesia, and other neurologically based conditions come to recognize their own differences as an integral part of their identity.

While conditions like the ones mentioned here can cause frustration, aggravation, and often result in having to face challenges in school, work, and other social settings, often the same conditions can offer advantages. For example, some dyslexic individuals tend to show strengths in spatial reasoning and creativity (Edie & Edie, 2012; Winner et. al., 2001). Some autistic individuals have a strong interest in information and patterns that form the basis of scientific thinking, contributing to an enhanced rationality (Mottron & Belleville, 1993; Rozenkrantz, 2020).

Futures studies, a cross disciplinary field, systematically explores possible, probable, and preferable futures, and in some cases encourages dialog between groups who have competing views of the future (Bell, 1996). Because of the variety of factors that can exert pressure upon the shape of possible futures, the cross disciplinary methods employed in the field tend to be complex. Methods described by Sardar and Sweeny (2015) and Melnikovas (2018) provide two examples of multilayered and flexible methodology for examining complex possible futures. Sardar and Sweeny's "Three Tomorrows" approach is designed to explore what might be next on a time horizon. This nonlinear approach examines a variety of potential outcomes, both familiar and unthought of. It accounts for the need to push out the boundaries of possibly incomplete information and interconnected events as we progress into

the future from these complex post-normal times. Milnikovas' methodological approach is also multilayered, often referred to as the "research onion" approach. His seven-step process adapted from the business studies work of Raithatha (2017) and Saunders, Lewis, and Thornhill (2016) involves induction, deduction and abduction -or inferences that are simplest and most likely use a combination of mixed-research methods while accounting for philosophy and time horizon. Given the chaotic nature of post-normal times, flexible combinations of methods are preferred.

This book will examine current conflicts surrounding the neurodiversity movement. Early chapters attempt to clearly outline neurodiversity's short history and endeavor to explain what neurodiversity is and is not, and to explore past and present trends and methods that make up the interdisciplinary field of futures studies. After a general consideration of both neurodiversity and future studies, both concepts will be employed to consider current conflicts and possible outcomes. The first and perhaps most salient concern is the relationship between the neurodiversity paradigm and the medical model. The neurodiversity movement is built upon the premise that individuals who are experiencing conditions such as ADHD, dyslexia, and autism are not "broken" or in need of a cure, while the traditional medical model often uses a deficit-based approach to understanding and treating these and similar conditions. A chapter is dedicated to these issues and a search for possible common ground where these two perspectives might meet.

The following chapter focuses on another major concern of the neurodiversity movement that grows out of the importance of members of the movement being involved in matters related to their lives. In this case the focus is on the process for establishing the research agenda related to the search for understanding of conditions like the ones mentioned here, as well as the quest for improving the quality of life for neurodivergent individuals as they tackle the many daily challenges of school, work, and other social encounters and relationships. Who will make decisions related to these research processes and how will the voices of important stakeholders be heard?

Most neurodivergent individuals first gain awareness of their own differences as they navigate the social challenges of elementary and secondary school. Many of those who go on to college and university struggle with their own different ways of perceiving and living in the world during their postsecondary experience in the even more complicated social milieus that exist on college and university campuses. A chapter is dedicated to discussing the educational experience of neurodivergent students as they pass through childhood, adolescence, and young adulthood, and explore their identities while in elementary, secondary, and higher education. As neurodivergent young people and adults increasingly come together and realize the many things they have in common, it is only natural to raise questions as to whether or not a new and distinct culture of neurodiversity is emerging. The achievements of the increasing numbers of individuals in this group, their belief systems, and features of daily living are certainly distinct enough to be considered as a culture. What this means for larger society will also be considered along with the impact of public policy and judicial systems.

Technological advances have played a crucial role in the short history of neurodiversity. In fact this new emerging culture is primarily a group of individuals loosely held together by the internet. The history of this important catalyst and its effect on education, developing neurodiverse communities, and the emerging culture will be examined. Understanding the role of rapidly evolving technology and what it will mean for neurodiversity is vital to understanding its future.

In short, the book delves into questions related to the future of neurodiversity.

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Chapter 1

Neurodiversity: What It Is and What It Isn't

Diversity is generally considered to be a good thing. Biodiversity brings richness to our environment and beauty to our natural landscapes. Social diversity provides variety within our social fabric giving us a range of life experiences to draw upon. As Dana Lee Baker (2011) puts it, "Diversity means strength. From our basic biology to international relations, a narrow attraction to sameness weakens the human experience." Neurodiversity is a social justice concept that views brain-based differences that manifest as conditions such as dyslexia, autism, and ADHD as forms of diversity. This increasingly influential point of view frames some conditions like those mentioned here along with other learning disabilities as natural variations in the human brain that confer both strengths and weaknesses. It is an alternative to deficit-based explanations for the conditions listed above as well as some other neurotypes.

Judy Singer first introduced the term neurodiversity in a thesis she submitted as a part of her studies in sociology at The University of Technology in Sydney, Australia, in the late 1990s (Singer, 1998). The paper, titled "Odd people in: The birth of community among people on the autism spectrum, A personal exploration of a new social movement based on neurological diversity," proposed the idea that neurological differences like autism should be recognized as a social category like race, class, and gender. This concept later spread through a handful of articles in the popular press that sought to extend human rights to people with different kinds of minds and different ways of being in the world. Singer believed that people with less visible differences like autism and some other neurological conditions were oppressed in the same ways that women and other minority groups were treated before the women's rights movement and the civil rights movement gained momentum.

While the history of human rights in Western society can be traced back to the Magna Carta in 1215, the English Bill of Rights in the late seven-

teenth century, and the U.S. Bill of Rights in the late eighteenth century, these historic documents were far from comprehensive in granting rights to individuals who were not white Anglo-Saxon men. The abolition of slavery by England and the United States in 1833 and 1865 respectively, brought humanity a step closer to comprehensive human rights, but it was not until the second part of the twentieth century that the reality of discrimination against people of color, women, and disabled people began to be addressed. In the wake of World War II, the newly formed United Nations General Assembly issued a “Universal Declaration of Human Rights.” Representatives from a variety of sociocultural backgrounds outlined the fundamental rights all human beings are entitled to including: 1. The right to equality 2. Freedom from discrimination 3. Life, liberty, and personal security 4. Freedom from slavery, torture, and degrading treatment (United Nations, 1948). Later in the 1960s and 1970s active civil rights movements in the United States and other parts of the world militated for equal treatment under the law for people of color. These movements fought against discriminatory practices that impeded access to education, jobs, public services, and housing.

The women’s movement in the United States gained a great deal of momentum during the sixties and seventies. With its roots in the women’s rights movement of the mid-nineteenth century, the ideas born in Seneca Falls calling for equality and the right to vote grew and bloomed during the second wave of feminism which focused on protecting women from violence and sexism, and began to recognize issues of intersectionality. Third wave feminism which emerged toward the end of the twentieth century worked to battle sexual harassment in work settings and to increase the number of women in positions of corporate and political power.

The Disability Rights Movement

Many see the neurodiversity movement as a significant extension of the disability rights movement (McGee, 2012). In some ways the history of the disability rights movement is similar to the history of the civil

rights and women's rights movements. All three have been in existence for more than one hundred years in one form or another, and gained substantial ground in the second half of the twentieth century. The history related to people with disabilities is a long one. For many years it has been a story of intentional marginalization. As often as people with disabilities were historically seen as objects of pity, they have been literally pushed aside, often kept out of sight through "placement" in state run hospitals and "schools." Institutions housing up to thousands of "inmates" as many with psychiatric difficulties were referred to, existed in many parts of the United States well into the 1970s. In the mid-twentieth century pediatricians often advised parents of autistic children to place them in institutions rather than to attempt to raise them in a home environment (Thompson, 2013).

In 1963, at the behest of his sister, John F. Kennedy signed the Community Mental Health Act. His younger sister, Rosemary, had an intellectual disability. Another Kennedy sister, Eunice, encouraged him to consider and support legislation related to mental health..."designed to use federal resources to stimulate local and private action. When carried out, reliance on the cold mercy of custodial isolation will be supplanted by the open warmth of community concern and capability" (Kennedy, 1963). Federal regulation encouraged the closing of large, often overcrowded, institutions by the late 1970s, but a lack of follow through in the creation of community based agencies to provide care for former occupants of large hospitals resulted in many living on the streets or in prisons.

The Rehabilitation Act of 1973 which prohibits discrimination on the basis of disability was an important milestone in the disability rights movement (United States Department of Health Education and Welfare, 1978). Section 504 of this act guarantees rights and protections and calls for reasonable accommodations for K through 12 and college and university students experiencing disabilities. It also applies to other organizations that receive federal assistance. The rights of individuals with disabilities in educational settings are further spelled out in the

Individuals with Disabilities Education Act (IDEA) which was passed in 1990.

In July of 1978, a group of nineteen men and women blocked intersections and the movement of busses in downtown Denver, Colorado. Using their wheelchairs to impede the progress of buses, they successfully protested the lack of accessibility to Denver's public bus system. "The Gang of 19" as they came to be known blocked busses chanting "We will ride!" until officials of the Denver Regional Transportation District agreed to meet with them to discuss their demands. This is an early example of a handful of individuals successfully militating for needed change by bringing a significant civil rights issue to public notice.

While Deaf culture has a long history, it gained significant momentum alongside the civil rights movement and with the passing of the Rehabilitation Act of 1973. It also previewed the emergence of neurodiversity culture which will be discussed in more detail in a later chapter. An important historical event in Washinton, DC, at Gallaudet University, then the only postsecondary institution exclusively serving the deaf population, took place in 1988. In a demonstration of the power of self-advocacy, students and faculty joined together to protest the appointment of a hearing president. After a week of protests, rallies, and demonstrations, the Deaf President Now movement influenced the appointment of Dr. I. King Jordan, the first deaf president of the university. This event is an example of the impact a relatively small group of individuals can have on the course of events. Deaf President Now "Has become synonymous with self-determination and empowerment" (Gallaudet University, n.d.).

IDEA, the law which makes a free and appropriate education (FAPE) available to children with disabilities, and Section 504 both work together with the Americans with Disabilities Act (ADA) passed in 1990 (Americans with Disabilities Act, 1990). In March of that year when the ADA legislation had stalled a group of about 1,000 protesters marched from the White House to the Capitol in support of the bill. There were several people in the group with mobility disabilities who set aside

their wheelchairs, crutches, and walkers, and crawled up the steps of the US Capitol to make a point about the need for the legislation. For many it was the first time they saw a wheelchair on television. George Bush signed the bill into law the following July.

A decade and a half later, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) reaffirmed the basic rights of disabled individuals to participate in civil, political, economic, social and cultural life of the communities they live in (UN,2006). All European Union countries, the United States, and scores of other countries have ratified this convention.

What Neurodiversity Is

If you ask several neurodivergent individuals what neurodiversity is, you will likely get a variety of answers that emphasize different aspects of the concept. Neurodiversity is complex and can be viewed from more than one perspective. It is a term used to cover identities linked to autism, attention deficit hyperactivity disorder or ADHD, dyslexia, and other neurodevelopmental differences. Neurodiversity recognizes almost endless possibilities in the way a very complex human genome results in the wide variety of human brains. Brain differences affect the way people experience the world and react to it. Neurodiversity recognizes that there is not just one normal or correct type of human brain. The concept of neurodiversity includes “neurodivergent people (those with a condition that renders their neurocognitive functioning significantly different from a “normal” range) and neurotypical people (those within that socially acceptable range)” (Kapp, 2020). The neurodiversity point of view recognizes the struggles and difficulties that people with conditions including autism, ADHD, dyslexia, and learning disabilities face as well as the possible benefits that can result from these conditions. In its early days the growth of neurodiversity was influenced by the autism acceptance movement, a part of the disability rights movement which saw autism as a part of identity. This idea spread rapidly in

the 1990s and early 2000s as individuals gained access to the technology that connected them via the internet.

Neurodiversity is an alternative to the medical model which often uses a deficit-based model to identify neurodevelopmental conditions as disorders that are in need of treatment and cure. Neurodiversity allows individuals to reframe their experiences, seeing differences as natural variations with advantages as well as disadvantages. They view themselves as not in need of fixing or broken. Many neurodivergent individuals see their neurologically based differences as an integral part of who they are. Their neurodivergence contributes a fundamental part of their identity in the same way that gender, race, class, or any other social category does.

Neurodiversity is also an emerging culture. Gloria Ladson Billings, professor of Urban Education at the University of Wisconsin, defines culture as “an amalgamation of human activity, production, thought, and a belief system” (Ladson-Billings, 1995). Other definitions include markers such as gender, ethnicity, immigrant status, shared knowledge, values, ability and disability and other salient aspects of social living when defining culture (Shmulsky et al. 2021). These definitions of culture recognize the neurodiversity community, and many members of the community see themselves as part of this emerging culture. The student population aged between three and 21 years old, 7.3 million students or up to 15% of public-school students received IDEA related services in the 2021-2022 school year (National Center for Education Statistics, 2023) forming a considerable number of potential members of an emerging culture. Members of the neurodiversity community are influenced by friends, family members, schools, and the media as they develop their identity within this new cultural context. The significance of neurodiversity as an essential element of identity is discussed in detail in Chapter 8.

The neurodiversity movement represents a rapidly growing force that addresses the concerns faced by many with the neurological conditions described here. Along with diversity, equity, and inclusion efforts,

neurodiversity seeks to reduce stigma and increase access to opportunities for education and work for neurodivergent individuals. While these efforts recognize intersectionality, the fact that each individual is affected by a range of social identities including race, class, gender, sexuality, and others into account, neurodiversity is becoming a powerful social movement that advances civil rights, respect, opportunity, and inclusion for neurodivergent individuals.

The core principles of neurodiversity are complex and evolving. Professor Jason Tougaw, author of *The Elusive Brain* describes neurodiversity as a kind of cerebral pluralism. He considers the almost endless variations in the ways neurodivergent individuals think and experience the world. The variability within diagnostic categories as well as the many combinations of co-occurring conditions that exist contribute to the variety of goals individuals within the movement may advocate for. Tougaw also predicts increasing political influence of this growing movement (Tougaw, 2020).

What Neurodiversity is Not

Not everyone agrees that neurodiversity is a good thing. Some disagree with the total concept; others disagree with one or two of the main underpinning ideas. Later chapters in this book will explore differences of opinion that surround a few of the fundamental ideas that neurodiversity rests upon. Some see neurodiversity as a way of discounting the real challenges of disability. They feel it whitewashes the lived experience of disability to make it appear to be a favorable thing. Others see it as covering up the difficulties and perhaps romanticizing or glamorizing the struggles associated with conditions like dyslexia, ADHD, and autism or other conditions discussed here. The frustrations, challenges, and pain are all very real. Some worry about possible consequences of deemphasizing the medical model. Others express concern that normalizing neurodivergence and the move away from deficit views used in traditional approaches to diagnosis will diminish accommodations and support available to those who require these to access educational

and career opportunities. Some of these inaccurate beliefs result from drawing a false dichotomy between diversity and disability (Shmulsky, 2022). The neurodiversity movement can perhaps be better understood as something layered on top of the disability rights movement (Ne’eman & Pelicano, 2022). While the previously mentioned federal regulations encouraged the building of a network of supports at all levels of education in the United States over the past 35 years, it is important to remember that since the passing of the Americans with Disabilities Act, it has been illegal to discriminate against individuals with disabilities. This is particularly pertinent when considering that the current level of unemployment is as high as 30-40% for neurodivergent individuals, eight times the rate of those without disabilities (Dunne, 2023).

Some disapprove of the neurodiversity movement because they feel it is just about exceptional individuals or individuals who score well on traditional measures of intelligence. They feel that it overlooks people who are nonverbal, or do not do well on these traditional measures, or have more severe versions of autism or other conditions. A neurodiversity view of these situations can only be more positive than a purely medical view. The neurodiversity model also recognizes that people can experience a great deal of positive change during a lifetime. A look at biographies of well-known autistic professionals like Temple Grandin (1986) or Melanie Yergeau (2018) attest to the possibility of positive change over a lifetime and vast change from the predictions of early diagnosis. The work of New Zealand artist Susan Te Kahurangi King demonstrates the possible virtuosic brilliance of an individual communicating through nonverbal means.

It is also important to keep in mind that people can present uneven ability profiles. Just because an individual exhibits strengths or weakness in one area, does not mean abilities in other areas are the same across the board. A person with strong expressive language abilities or strong language skills can possibly have weak social judgment. A person with strong visual spatial skills may have weak expressive language skills. Neurodiversity is not a “one size fits all” approach. The movement includes a wide range of experience, conditions, and degrees of

severity. Neurodiversity allows for all neurodivergent individuals to reframe their experience in a positive light. It allows them to be less critical of themselves just as it allows neurotypical people a new way of understanding and of being open to individuals with neurologically based differences.

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Chapter 2

A Brief History of Neurodiversity

The history of medicine is as long and complicated as the history of Western Civilization. For the last century or longer it has held dominion over the conditions ordinarily gathered under the umbrella of neurodiversity. The formal “unified” history of the description and diagnosis of ‘mental disorders’ in the United States goes back over seventy years. In 1952, a manual of mental disorders known as the *Diagnostic and Statistical Manual of Mental Disorders* or *DSM* was approved and published by the American Psychiatric Association (1952). Since then, it has described some neurodivergent conditions including autism and ADHD, and it has not included others such as synesthesia. Dyslexia was recently reintroduced into the fifth edition of the DSM in 2013 after being referred to as a reading disorder in the DSM IV. Over the years the diagnostic manual has included conditions considered to be pathological including homosexuality, which was removed in 1973, and gender identity disorder was changed recently to gender dysphoria. While descriptions of autism and ADHD have recently been revised, in both cases they are presented using a deficit model of diagnosis. The neurodiversity approach views these same two conditions as natural variations rather than deficits (Armstrong, 2012, 2010) and focuses on changing society rather than identifying individual deficits. This view of difference rather than deficit is a cornerstone of the neurodiversity movement.

One important concept that has helped to expand the view of cognitive abilities grew out of the work of Howard Gardner, professor at the Harvard Graduate School of Education. Gardner proposed that there are several intelligences in addition to the verbal and logical-mathematical intelligences which are measured by traditional tests of intellectual capacity. He and his associates recognized different kinds of learning and went on to establish what became known as the theory of multiple intelligences (MI). His early view of MI included seven intelligences (Gardner, 1983). He later added two more (Gardner, 1999). His current

view includes nine intelligences: verbal-linguistic, mathematical-logical, musical, visual-spatial, bodily kinesthetic, interpersonal, intrapersonal, naturalistic, and existential. His broadening definition allows for the recognition of intelligence often demonstrated by individuals with brains that may be wired differently than those who excel at verbal-linguistic and or mathematical-logical definitions of intelligence.

...*...

In my work as a psychology instructor the ideas of Howard Gardner figured prominently for several years. This was, in a large part, because I worked with groups of dyslexic students at Landmark College in Putney, Vermont. The college was founded in 1983 by Chad Drake, a forward-thinking educator who followed through on his idea to open a college for students with learning disabilities. This was a bold, even radical idea, especially in the 1980s when many small institutions of higher education struggled to survive. Even before the term neurodiversity was coined Landmark College had a neurodiversity mission. The faculty at Landmark understood that students who learned differently needed to be taught differently. Before the term universal design entered the vocabulary of education, Landmark instructors taught multimodally. In my psychology classes I spent a great deal of time helping students to understand the basic ideas related to the structure and functioning of the human brain and nervous system and the relationship between brain differences and behavior. We talked about the work of Albert Galaburda (2005) and other researchers, and how language processing could perhaps be different in dyslexic individuals. This of course was connected to the discussion of Howard Gardner's different kinds of intelligence other than that related to language, logic, and mathematics, and their relationship to the possibility of a "brain basis" for these differences. Or the idea that specific neural networks underpin specific intelligences.

Over the next forty years the college would begin to receive students who primarily had difficulty related to attention and executive function, and developed instructional and coaching techniques that would

increase their chances of academic success. Later, about fifteen years ago, we began to work with increasing numbers of autistic students in our classrooms. Most of them had strong academic skills but struggled with social pragmatic concerns. While working with our students, whether they struggled with language processing, executive function, or social pragmatics, we often discussed an essential question, “Do you have a learning disability, or do just learn differently?” Most students concluded that they learned differently, but had a disability if they needed to qualify for support services or accommodation.

By the year 2000 we also had the term neurodiversity to include in our discussions. Judy Singer’s idea was gaining traction. While Landmark College always had a “neurodiversity mission,” in the 2010s along with other colleges in the United States such as Drexel University and The College of William and Mary, Landmark College founded a center for neurodiversity on campus.

...*

Even though educators and students at Landmark and probably at other colleges and universities were discussing ideas closely aligned with what would later be referred to as neurodiversity, the history of the movement is often traced back to the work of Judy Singer and her thesis ideas which Harvey Blume later wrote about and published in *The Atlantic*. His article titled “On the Neurological Underpinnings of Geekdom,” introduced neurodiversity to a wide readership (Blume, 1998).

A few of neurodiversity’s essential philosophical concepts surfaced in other areas before Singer’s work became well known. Many trace the origins of the neurodiversity movement to the work of Jim Sinclair, one of the founders of ANI, Autism Network International. In 1993 at a small International Conference on Autism held in Toronto, Canada, Sinclair (1998, 2012) gave a talk, later published in *Our Voice*, ANI’s newsletter. This presentation titled, “Don’t Mourn for Us,” had as its target audience parents of autistic individuals. It discussed the grief parents felt over the loss of the expected childhood experiences of their autistic children. Sinclair encouraged parents not to mourn for “what never

was but to explore what is.” This was a very different approach than that taken by prominent autistic writers of the time who talked about overcoming autism and emphasized the negative experiences associated with the condition (Pripas-Kapit, 2020). Sinclair provided a new view of autism. Xe’s (Xe is Sinclair’s preferred pronoun.) work encouraged parents to move beyond disappointment and then to relate to and communicate with their autistic children. Xe’s presentation and later work emphasized the importance of autistic people gathering together to learn from one another. This work opened the door to the “double empathy” problem. This concept explains some of the social difficulties faced by many neurodivergent individuals from a lack of mutual understanding or differences in communication styles of both neurodivergent and neurotypical individuals involved in a social exchange (Milton, 2021). Sinclair also raised the need for neurotypical people to question their assumptions about autistic people and consider autistic individuals in the ways one might think about individuals from a different culture.

At about the same time as Sinclair’s work became noticed, Oliver Sacks, well known author, neurologist, and talented writer of case studies, introduced Temple Grandin to the world in his bestselling book *An Anthropologist on Mars*, a collection of seven case studies of individuals with neurological conditions (Sacks, 1995). Grandin, an autistic professor of animal science at Colorado State University, was then known for her development of humane systems for the treatment of livestock. She is now also known as a leading advocate for autistic and neurodivergent people.

As mentioned earlier, in the late 1990s Judy Singer gave the world the term neurodiversity. It provided a word to use when referring to a large group of people who think and act differently because of their neurological differences. Perhaps her original intentions were not as expansive as the movement that took her term to represent what it stood for. When she first wrote about neurodiversity she was thinking about her mother (and later her daughter) who experienced social difficulties. Later their situations would be described as Asperger’s syndrome. A

term used between 1994 and 2013, Asperger's syndrome described individuals with social interaction and nonverbal communication concerns that interfered with daily functioning. Singer had the foresight to see neurodiversity as an identity like gender or race (Lutz, 2023), but over the next two decades it became something much larger than she anticipated or imagined, or perhaps intended. According to historian Amy Lutz, Singer has since introduced a new term, *Neurorealism*, as a counter to what she thinks can be an overly optimistic view of neurodiversity. She hopes this will refocus attention on the actual needs of neurodivergent individuals, her original use of the term referred to those with Asperger's syndrome with normal to high intelligence as measured by standard instruments. Neurorealism recognizes that autism is not a unitary condition and those who experience it have a range of support needs. Neurorealism emphasizes collaboration among "autistic adults, families, researchers, clinicians, and health providers," all of whom are important stakeholders with voices that deserve to be heard.

Between the time of Singer's introduction of the term and its recent reiterations, many autistic individuals have distinguished themselves through impressive work that has benefited many. In 2002, Vernon L. Smith, an autistic professor of economics, became the first openly autistic individual to be awarded a Nobel Prize. Smith developed his innovative ideas about experimental economics in the 1980s in part through his novel teaching and classroom experiments (The Decision Lab, n.d.). Dr. Smith stated that, he "didn't have trouble thinking outside the box. I don't feel pressure to do things the way other people do. So, I have been more open to different ways of looking at a lot of problems in economics" (Herrera, 2005).

Two years later in 2004 the word about neurodiversity was gaining momentum with the first website Neurodiversity.com appearing online. It discussed the "variety of human wiring." By this time with an increasing number of students and members of the general population gaining access to personal computers and the internet, the spread of information through this medium, which many members of the neurodiversity community had a penchant for, was rapid and extensive. At

this time neurodiversity was continuing to make headlines both online and in print media. In May of 2004, Amy Harmon's article "Neurodiversity Forever; the Disability Movement Turns to Brains" was featured in the *New York Times*. She discussed the emergence of a new movement, the role of Howard Gardner's work, and the internet in the process (Harmon, 2004).

2006 marked the first celebration Neurodiversity Day. It was held on the same day as Autistic Pride Day which was first celebrated by Aspies for Freedom. It is traditionally held on June 16th. Two years later, John Elder Robison (2008), who later became a well-known neurodiversity advocate published his autobiography, *Look Me in the Eye*. Robison sees and writes about his neurodivergence as a part of his identity. Around the same time, Daniel Tammet (2007), an autistic synesthetic linguist published his memoir titled *Born on a Blue Day*. His remarkable abilities in the fields of linguistics and mathematics are discussed in his book which encourages others to embrace their differences as he did, and to use them to meet the challenges they face.

In 2009, Carol Greider claimed a Nobel Prize for her work in the field of molecular biology. Dr. Greider, who experienced dyslexia, was able to use her compensatory skills and her ability to pull ideas out of context and combine them in new ways to solve scientific problems (Crockett, n.d.).

By the second decade of the twenty-first century the concept of neurodiversity and the neurodiversity movement were gaining even greater traction with the general public. The book *Neurotribes* by Steve Silberman (2015) became a best seller. His book spread the basic ideas of neurodiversity, discussing autism, its history, and encouraging research that focuses on the needs of the autism community. The research literature on neurodiversity has also increased steadily during this time period with *Disability Studies Quarterly* dedicating an entire issue to autism and neurodiversity. The issue was representative of the trend of increasing numbers of contributions by neurodivergent researchers. This event was followed by peer reviewed journals such as *Autism* and *Autism in*

Adulthood adding neurodivergent researchers to their editorial boards. The political impact of the movement is also beginning to be felt with autistic representatives to government advising groups, and in a very direct way with the elections of Jessica Benham and Yuh-Line Niou, both openly autistic women, to the Pennsylvania and New York State legislatures. Today Centers for Neurodiversity are being established at colleges and universities following the models of early adopters and embracers of the idea such as Landmark, Drexel, William and Mary, and others. Neurodiversity Studies is becoming an established interdisciplinary academic field “aimed at advancing the epistemic and ideological rules that govern and produce “normal” and “others” according to scientific, cultural, and social practices” (Dind, 2021). With it becoming an academic field, time has arrived to examine the controversies related to neurodiversity and their possible outcomes.

Chronology

History of Neurodiversity

1970	Physically Disabled Students Program founded at UC Berkley
1975	Individualized Education Plans (IEPs) first introduced after passing of the Education for All Handicapped Children Act
1982	Howard Gardner publishes his theory of Multiple Intelligences
1984	Center for Applied Special Technology (CAST) founded to support Universal Design for Learning
1986	Temple Grandin publishes <i>Emergence: Labeled Autistic</i>
1990	The Americans with Disabilities Act (ADA) signed into law
1991	Donna Williams publishes <i>Nobody Nowhere</i>
1995	Oliver Sacks publishes <i>An Anthropologist on Mars</i> which profiles Temple Grandin
1997	Harvey Blume publishes the article “Neurological pluralism” in the <i>New York Times</i>

- 1998 Harvey Blume publishes the article “On the neurological underpinnings of geekdom” in *The Atlantic*
- 1998 Judy Singer completes thesis “Odd people in: The birth of community amongst people on the autistic spectrum.”
First use of the term neurodiversity
- 2002 Economist Vernon E. Smith becomes the first openly neurodivergent person to be awarded a Nobel Prize
- 2004 Amy Harmon publishes “Neurodiversity forever” in the *New York Times*
Prominent website Neurodiversty.com is set up by Kathleen Seidel
- 2006 Autistic Pride Day and Neurodiversity Day first celebrated by Aspies for Freedom
- 2007 United Nations declares World Autistic Awareness Day
Daniel Tammet publishes *Born on a Blue Day*
- 2008 Nick Walker introduces the term neuroqueer and explains neurodiversity vocabulary in his website neuroqueer.com
John Elder Robison publishes *Look Me in the Eye*
- 2009 Carol Grieder, neurodivergent molecular biologist, is awarded Nobel Prize
- 2010 Rise of identity first language in academic writing
- 2012 United Nations adopts resolution 67/82 which addresses the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders
- 2015 Steve Silberman publishes *Neurotribes: The Legacy of Autism and the Future of Neurodiversity*
- 2018 Melanie Yergeau publishes *Authoring Autism*

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