1

Introduction

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This book marks the first historical overview of the autistic community and the neurodiversity movement that describes the activities and rationale of key leaders in their own words. All authors of the core chapters consider themselves part of the autistic community or the neurodiversity movement (including a couple among the growing legion of non-autistic parents), or both in most cases. Their first-hand accounts provide coverage from the radical beginnings of autistic culture to the present cross-disability socio-political impacts. These have shifted the landscape toward viewing autism in social terms of human rights and identity to accept, rather than as a medical collection of deficits and symptoms to cure. The exception to personal accounts and part of the impetus for the book, Jim Sinclair, has become inactive since leading the autism rights movement's development

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of culture and identity after co-founding its first organization Autism Network International (ANI) in 1992. Yet this book respects the disability rights motto of "Nothing About Us Without Us" by commissioning an autistic historian and chairperson of an organization inspired by ANI's historic autistic community retreat to analyze the context and impact of Sinclair's legendary work. Similarly, I am an autistic neurodiversity activist (a role that precedes my career as an autism researcher), but I endeavor to apply robust scholarly standards to editing this collection (see the Preface).

Introduction to the Neurodiversity Movement

Many descriptions arguably misunderstand the concept of *neurodiversity* and the framework and actions of the *neurodiversity movement*, so this chapter seeks to explain them before introducing the core chapters.

The term *neurodiversity* originates from the autism rights movement in 1998 from Judy Singer on Martijn Dekker's mailing list InLv, but as the movement has matured into a more active part of a cross-disability rights coalition, the term has evolved to become more politicized and radical (a change noted by a few contributors, especially Dekker in Chapter 3). *Neurodiversity* has come to mean "variation in neurocognitive functioning" (p. 3) [1], a broad concept that includes everyone: both *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). The *neurodiversity movement* advocates for the rights of neurodivergent people, applying a framework or approach that values the full spectra of differences and rights such as inclusion and autonomy. The movement arguably adopts a spectrum or dimensional concept to neurodiversity, in which people's neurocognitive differences largely have no natural boundaries. While the extension from this concept to group-based identity politics that distinguish between the neurodivergent and neurotypical may at first seem contradictory, the neurodiversity framework draws from reactions to *existing* stigma- and mistreatment-inducing medical categories *imposed* on people that they *reclaim* by negotiating their meaning into an affirmative construct. People who are not discriminated against on the basis of their perceived or actual neurodivergences arguably benefit from neurotypical privilege [2], so they do not need corresponding legal protections and access to services. I have observed little serious aggrandizement of neurodivergent people or denigration of neurotypical people, but satire has been misinterpreted (Tisoncik, Chapter 5) or rhetoric misunderstood due to disability-related communication or class differences.

The Diversity in *Neurodiversity*

Although the people for whom the neurodiversity movement advocates far exceed autistic people, they also fall outside the main scope of the book. Some contributors' topics do include campaigns directly affecting people with other disabilities, such as that to close the tortuous Judge Rotenberg Center in the U.S. (Neumeier and Brown, Chapter 14) and to pass the Autism/Neurodiversity Manifesto in the U.K. (Craine, Chapter 19), yet the movement remains led by autistic people. Mainly though, the scope of the movement remains unclear; at a disability studies conference I asked participants how they felt about minimum criteria for eligibility within it, but they felt uncomfortable posing limits [3]. A woman suggested her multiple sclerosis should qualify; indeed, coverage of people with not only chronic illnesses but also primary sensory disabilities like blindness and psychiatric conditions like schizophrenia remain unclear [4]. One issue may be the importance of the cure issue to the movement; for example, an autistic neurodiversity activist advocates for acceptance for autism but a cure for epilepsy (which she sees as separate from her sense of self and understands as potentially fatal). Such neurological conditions fall within the broader disability rights movement and deserve basic rights accommodated, such as, arguably, policy to ban flash photography in public places that could trigger seizures in people with photosensitive epilepsy [5]. The primacy of biology to the movement seems clear due to the *neuro-* in *neurodiversity*, and debates as to whether relevant neurodivergences must be neurodevelopmental or can be acquired environmentally or in adulthood have taken place in the U.K. [6]. Conditions such as schizophrenia fall within another identity-based socio-political movement (the mad pride movement, and while the neurodiversity movement may help provide a bridge to the disability rights movement, many adherents do not view themselves as disabled [7]. More importantly and practically, campaigns to attribute these conditions to the brain have backfired, likely because the public often associates them with violence and thinks brain-based conditions are more difficult to treat [8, 9]. Ultimately, book contributors did not exclude any particular conditions from the domain of the movement, and the right to self-determination offers the opportunity for other people to identify and organize within the movement.

While some activists say *neurodiversity* refers simply to a biological fact of this variance as opposed to the movement [10, 11], contributors to this volume—as aware autistics do generally: see Preface—suggest the term implicitly refers to a tenet of inclusion based on universal rights principles, with an emphasis on those with neurological disabilities. This includes aspirations of full inclusion in education, employment, and housing; freedom from abuse (e.g. abolition of seclusion and both chemical—that is, overmedication to control behavior—and physical restraint); and the right to make one's own decisions with support as needed. Contributors evoke "the compassionate, inclusive flavor of the word" (Seidel, Chapter 7) and "human rights concept" (Greenberg, Chapter 12): "the specific premise of neurodiversity is full and equal inclusion…Neurodiversity is for everyone" (daVanport, Chapter 11). Buckle (Chapter 8) clarifies that this inclusion involves interaction between diverse groups even in settings prioritized around the needs of a particular group: neurodiversity "means having NTs [neurotypicals] in autistic space as much as it does autistics in NT space". Raymaker (Chapter 10) explains both parts of the compound word: "Neurodiversity, to me, means both a fabulous celebration of all kinds of individual minds, and a serious, holistic acknowledgement of the necessity of diversity in order for society to survive, thrive, and innovate", which as Garcia (Chapter 17) states requires that society "welcome neurodivergent people and give them the tools necessary to live a life of dignity". Inspired by the principles of other social justice movements, the neuro*diversity* movement recognizes intersectionality (how neurodivergent people's disadvantages are compounded by other types of social oppression) beyond cross-disability solidarity, such as race (see Giwa Onaiwu, Chapter 18), gender including gender identity (see daVanport, Chapter 11), and class (such as the call by Woods [2017] for universal basic income).

Like the far-reaching concept of *diversity*, the neurodiversity movement as applied to autism functions inclusively, in that activists include non-autistic people as allies, and it accepts and fights for the full developmental spectrum of autistic people (including those with intellectual disability and no or minimal language). Marginalization of non-autistic people by non-autistic relative-led autism organizations catalyzed the movement (Pripas-Kapit, Chapter 2; [12]). Thus it seeks to help families with advocacy for acceptance, understanding, and support that can positively impact people across the autism spectrum and their parents [13]. Celebratory acts for parents toward autistic children such as learning to speak their child's language and even accepting autism as part of their child's identity, and ameliorative acts like parents teaching their child adaptive skills to cope in wider society, both show nearly universal support among the autism community—including "pro-cure" parents and "pro-acceptance" autistic people [14], yet many of the more powerful parental organizations have behaved in dehumanizing and polarizing ways toward autistic people, such as using fear and pity as fundraising strategies and seeking an end to all autistic people regardless of their preferences (daVanport, Chapter 11). They have appropriated self-advocacy by using language such as "families with autism" (whereas if anyone "has" autism, autistic people do). They have also claimed autistic people cannot advocate for public policy affecting their children (even though some autistic activists themselves have intellectual disability, language impairment or no speech, epilepsy, gastrointestinal disorders, self-care needs such as toileting or daily living, meltdowns, etc., or their children do: [15, 16].

The *Neuro-* in *Neurodiversity*

While the neurodiversity movement generally views autism as natural and essentially innate, despite the inability of clinicians to identify it from birth, this viewpoint transcends politics despite its utility in activism. Autistic people tend to view autism as arising entirely from biological causes, with no evident influence from the movement [14]. This may occur both because autistic people likely cannot remember their life before autism becomes diagnosable, and because autistic people more often conceive of and describe autism from the inside, referring to internal processes such as thoughts, emotions, and sensations rather than behavior [17]. This conception of autism privileges lived experience, and complements autistic activists' arguments that underlying differences and difficulties persist despite coping mechanisms that may behaviorally "mask" autism, which have support from neuroscientific and other research [18]. Such a phenomenon helps autistic people counter the attack "You're not like my child" from parents; see the group blog We Are Like Your Child (http://wearelikeyourchild.blogspot.com/). It also facilitates a neurological kinship of sorts with fellow autistic people, helping us to emphasize within-group commonalities to develop a sense of community despite variability in how our behaviors present, and to argue for our rights based on what Silverman [19] calls "biological citizenship". An inside-out viewpoint of autism also helps advocates of neurodiversity explain adaptive reasons *why* autistic people engage in atypical behaviors, such as "stimming" (e.g. body rocking and hand flapping: Kapp et al. [20]; Schaber [21].

Importantly, brain-based explanations facilitate the movement's compatibility with alliances with non-autistic parents. They reject a role in caregiving for causing autism, absolving parents of the responsibility scientists and clinicians assign(ed) to them when Freudian psychogenic theories have dominated (as they still do in France and to a lesser extent in countries such as Brazil). This may reduce parents' aversion toward listening to neurodiversity advocates describe helpful parenting practices. Many of the more successful "therapeutic" approaches involve educating others to respectfully understand autistic people's differences, such as teaching *responsive* caregiving tactics to parents that require them to "learn to speak their child's language" and communicate on their terms [13]. Researchers developed these techniques based on successful positive parenting practices in general [22]. A model that allows more for environmental contributions to autism's causation might look like parent-blaming, sparking resistance, and stifling progress. Moreover, biological explanations argue against environmental toxins as a risk factor for autism, helping to direct parents away from cottage industries based on rejected and unproven theories that offer dangerous “treatments” like heavy metal-injecting chelation therapy, chemical castration (Lupron therapy) bleach enemas, and vaccine avoidance (amid other expensive or at least ill-conceived “interventions”). Instead, biological explanations led by the neurodiversity movement help to raise ethical concerns about the basic scientific research that dominate autism research (such as the possibility of eugenics; see Evans, Chapter 9).

Interaction with the Medical Model

Although many claim that the neurodiversity movement simply supports the social model of disability and opposes the medical model, neurodiversity activists instead acknowledge the transaction between inherent weaknesses and the social environment [23, 24]. The social model of disability distinguishes between the core *impairments* inherent to medicalized conditions and *disability* caused by societal barriers (e.g. lack of assistive technology and physical infrastructure to enable someone with a mobility disability to move where they want to go), which for autism especially include social norms that result in misunderstandings and mistreatment [25]. One of the social model originators Mike Oliver [26] explained that he never advocated it as all-encompassing or intended it to *replace* the individual (medical) model, but to serve as an academic-political tool to help empower disabled people by emphasizing attention to the social obstacles that unite us; that it has certainly done. Yet the impairment that the model separates from disability may certainly add to any individuals’ struggles. In practice this means that the neurodiversity movement begins with its goal of quality of life, which includes but surpasses adaptive functioning (e.g. self-determination and rights, well-being, social relationships and inclusion, and personal development: Robertson [27]; see also Tsatsanis et al. [28]), and works backward from there to address the individual *and* social factors that *interact* to produce disability. In contrast, a “pure” medical model approach would assume an individual’s “symptoms” (behaviors or traits) directly and specifically cause dysfunction or disability, and work to disrupt this linear relationship by preventing or curing the condition. Yet the disability rights movement has already helped enshrine access (e.g. reasonable accommodations) and non-discrimination into law, and medical practices have gradually changed to allow more patient and client autonomy [29]. Indeed, social and medical models have moved toward one another over time [24].

The neurodiversity movement's opposition to "curing" autism has produced misunderstandings, such as mistaken assumptions that it attributes all challenges to social injustices and rejects interventions to mitigate them. While the movement disagrees with certain principles, means, and goals of interventions, with those caveats, it does support therapies to help build useful skills such as language and flexibility. It opposes framing these matters in unnecessarily medical or clinical ways; arguably all interventions that have a scientific evidence base for truly helping autistic people's core functioning involve active learning (by the autistic person or others), and therefore one might describe them as "educational". It recognizes that some behaviors associated with neurodivergences like autism can serve as strengths (such as interests), as coping mechanisms for underlying differences that can prove challenging at times (such as forms of stimming like hand flapping and body rocking, which help to self-regulate and communicate overpowering emotions, among other functions: Kapp et al. [20]; Bascom [30]), or as inherently neutral differences (such as an apparently monotone voice or a preference for solitude: Winter [31].

While all social movements have more radical left wings, arguably the organized, politically mobilized autism rights branch of the neurodiversity movement largely practices critical yet reformist pragmatism rather than revolution. The movement in some ways supports a Western biomedical model more than autism's medical establishment and certainly more than autism's organized cure movement. For example, the neurodiversity movement's framework conceptualizes autism itself as purely biological, as opposed to resulting from dynamic genetic-environmental interplay (as the mainstream autism field believes and as most research suggests) or at least in part from toxins in the physical environment (as many "pro-cure" parents and their advocacy organizations have believed). Neurodiversity activists support traditional medicine for preventing and treating ill health, such as vaccines to prevent infectious diseases and (with the individual's consent) psychotropic medication to treat anxiety and depression (see Murray, Chapter 4), whereas beliefs in the likes of false and discredited vaccine-autism links have energized radical pro-cure activists, pseudoscience, and fringe medicine.

Neurodiversity supporters cling essentially to autism's diagnostic criteria when challenging even mainstream critics, as we support acceptance of official autism domains of atypical communication, intense and "special" interests, a need for familiarity or predictability, and atypical sensory processing, yet distinguish between those core traits and co-occurring conditions we would be happy to cure such as anxiety, gastrointestinal disorders, sleep disorders, and epilepsy. We, as do all of the authors for this book and the latest revisions of autism's official diagnoses ([32]; https://icd.who.int/), generally support a unified conception of the autism spectrum. Understanding and production of structural language now fall outside of autism's criteria (as a separate communication diagnosis), and neurodiversity activists have likewise supported efforts to expand access to language and communication but do not regard this as making someone "less autistic", unlike arguably most autism advocates. Autistic neurodiversity activists have defined critical autism studies not in terms of being critical of autism's existence (unlike many non-autistic thinkers outside the movement), but of the power dynamics that marginalize autistic scholars, pathologize autism, and overlook social factors that contribute to disability in autistic people [33]. While we support moving to an alternative identification system that recognizes autism's nuances ([34]; Kapp and Ne'eman, Chapter 13), such as strengths that can aide or add difficulties to autistic people's lives depending on myriad factors [35], the often fractious autism community united around the need to protect autistic people's access to diagnosis because of the practical services and supports medical classification can provide. While the psychiatric and clinical establishment sharply criticized the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM) for *adding* and *expanding* most diagnoses (increasing medicalization of everyday problems) in its latest revision (DSM-5) or for lacking validity [36], the neurodiversity movement's leading organization the Autistic Self Advocacy Network (ASAN) worked more closely with the DSM-5 than any other in the autism community to protect access to diagnosis (Kapp and Ne'eman, Chapter 13).

Self-Advocacy

The neurodiversity movement's approach holds autistic and neurodivergent people responsible not for the origin of our problems (social barriers exacerbating biological challenges), but for leading the effort to solve them. This position—responsibility for the "offset" but not "onset" of problems—aligns with the compensatory model of helping and coping according to an analysis [37] of a classic theoretical paper [38]. Other identity-based social justice movements such as the civil rights movement share this approach, which Brickman and colleagues viewed as arguably superior because it encourages people to seek help (because it does not blame people for problems), yet actively exert control over their lives. Yet while they say on page 372 that the model "allows help recipients to command the maximum possible respect from the social environment" and enables mobilization, people oriented this way put enormous pressure on themselves to solve problems they did not create, risking distressing strain. Indeed, campaigners in this book noted the financial and sometimes emotional sacrifices made for their activism (Murray, Chapter 4; Seidel, Chapter 7; see also Pripas-Kapit, Chapter 2). Movement activists do not think neurodivergences like autism excuse abusive behavior, and call it out (especially in intersectional ways to protect more disempowered community members), such as educating autistic men about consent in sexual relationships (Garcia, Chapter 17; [39]). In contrast, the medical model holds people responsible for *neither* the causation of *nor* the solution(s) to their problems, making them dependent [38], albeit medical and clinical clients in general have become increasingly empowered in practice [29].

History and Introduction to Contributors

I commissioned contributors who have made significant achievements to the development or maturation of the autistic community or the neurodiversity movement. I posed the same questions to all contributors for them to consider: why and how they got involved, how they carried out their contribution, whether it has accomplished what they intended, etc.

Contributors took different approaches to addressing these questions, and while I suggested a topic (originally limited to a particular action) and length, they negotiated their preferences and needs with me. I chose to prioritize content rather than style in my editing, giving substantive feedback on drafts but deemphasizing grammar and structure, especially considering contributors' wide-ranging educational and cultural backgrounds as well as communication abilities, to preserve the voices of the activists (see also Giwa Onaiwu, Chapter 18).

The chapters follow a chronological order that reveals patterns in the growth of the neurodiversity movement over time, a historical orientation that emphasizes where the movement and autism field have been most active: the U.S. and U.K. (the home of all contributors except Dekker, who lives in the Netherlands but also spends significant time in the U.K.). These countries have had exceptional roles in pioneering mother-blaming psychoanalytic child psychology that have unjustly blamed parents and sometimes removed autistic children from them, giving rise to the first autism advocacy organizations [40, 41]. Those parent-led organizations empowered both world-leading scientific research and pseudoscience to establish autism as a treatable developmental disability [42]. Yet these nations also arguably hosted the birth of the disability rights movement (in the U.S.), the social model of disability (the U.K.), and disability studies (arguably both countries; see Waltz, 2013). Hence autistic adults had more to resist and resources at their service in these contexts, with similarities in various other anglophone countries and nations with high English fluency. Furthermore, most activities of the neurodiversity movement have taken place online, where people can participate internationally. This organizational approach to the book not only reflects not wishing to oversimplify other national and cultural contexts (e.g. Germany or Israel) with single chapters, but also the limitations of where I have lived and my social networks.

Part I: Gaining Community

At a time when non-autistic parents dominated autism advocacy in the early 1990s, Sinclair (Chapter 2) led the launch of the movement and delivered its pro-acceptance manifesto mainly intended for parents, “Don’t Mourn for Us”, helping autistic people gain an identity and communicate in cyberspace (ANI-L) and in person (Autreat). In 1996, Martijn Dekker’s e-mail list InLv provided an inclusive, autistic-hosted space that helped spawn new ideas such as the term *neurodiversity* (Chapter 3). By 1998 Autistic activists demonstrated their ability to partner and ally with parents and non-autistic professionals on early campaigns they led, such as Dinah Murray’s “Autistic People Against Neuroleptic Abuse” (Chapter 4). Laura Tisoncik’s autistics.org website launched that year and gave voice to injustices such as through satire like the Institute for the Study of the Neurologically Typical (Chapter 5), yet now “neurotypical” has become a common descriptor for people without neurological disabilities in medical studies. Protest campaigns in response to specific events and initiatives have mounted, such as Mel Bagg’s Getting the Truth Out website created in 2005 in response to the Autism Society of America’s fear-mongering Getting the Word Out (Chapter 6), along with ongoing efforts like Autistics Speaking Day in response to Communication Shutdown and Autism Acceptance Day and Month in response to their Autism Awareness counterparts. The movement has grown to create annual events by autistic activists not in specific response to those by non-autistic people, including Autistic Pride Day launched by Amy and Gareth Nelson in 2005 and the Disability Community Day of Mourning, begun by Zoe Gross in 2012 to remember those people with disabilities murdered by family members and try to prevent future filicide.

Part II: Getting Heard

These activities have helped raise consciousness that the neurodiversity movement, while arising to counter the exclusion and pathologization autistic adults felt by organizations and conferences run mainly by non-autistic parents, serves to create a world where autistic and other disabled people are free to be themselves in a respectful and inclusive society. Indeed, Kathleen Seidel (Chapter 7) has hosted neurodiversity.com as a non-autistic parent, without significant protests that an autistic does not own the domain name (Chapter 7). The historic archives, posts by autistic and non-autistic guests on debates or issues, and Seidel's counters to disinformation like false, dangerous treatments for and beliefs of causes of autism have demonstrated the movement's alliance with like-minded parents and impactful commitment to science.

Inspired by Sinclair's Autreat, Autscape (Buckle, Chapter 8) provides the longest-running ongoing example of physical "autistic space": an annual conference mostly by and for autistic people, which has demonstrated the possibilities and limits of inclusion. Beginning at a similar time, the Autistic Genocide Clock webpage publicized autistic people's fears of eugenics to prevent autism through the development of a genetic test for selective abortion, and its creator Meg Evans (Chapter 9) took it down early mainly because of the progress of the neurodiversity movement in changing attitudes toward acceptance. During the time span between the autism genocide clock being created (2005) and taken down (2011), ASAN led the movement's maturation from a sociocultural to a sociopolitical movement actively part of the disability rights coalition, organizing a protest against a cross-disability campaign that united autistic people with parents of autistic individuals and disability rights activists alike [43].

The Academic Autism Spectrum Partnership in Research and Education (AASPIRE) project has demonstrated the expertise of even lay autistic people as the leading provider of participatory autism research (Raymaker, Chapter 10), illustrating the growing reach of the neurodiversity movement, as have other developments. The Autistic Women and Non-Binary Network (AWN) has provided powerful advocacy for intersectional feminism, as exemplified by its recent selection by the U.S. Library of Congress for preservation of its website, giving access to archives for current and future generations of advocates (daVanport, Chapter 11).

The Thinking Person's Guide to Autism provides a network of pro-neurodiversity and pro-science information hosted by autistic and non-autistic parents, providing the neurodiversity movement with an influential alliance that helps to reach the critical demographic of non-autistic parents (Greenburg and Rosa, Chapter 12). ASAN consulted on the revision of autism's diagnosis in the DSM-5, marking a historic collaboration that substantially affecting the core criteria and accompanying text to help maintain access to autism diagnoses and therefore needed supports (Kapp and Ne'eman, Chapter 13).

Shain Neumeier and Lydia Brown (Chapter 14) have taken leading roles in activism to stop the electric use of shocks as "treatment", raising the profile of the issue and providing strong legal and ethical arguments that have assisted progress toward banning the tortuous practice.

Larry Arnold (Chapter 15) edits *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, a journal that not only advances the cause of autistic people as editors and authors of new academic studies, but also preserves key texts of the neurodiversity movement.

John Elder Robison (Chapter 16) served as the only autistic advisor to Autism Speaks, the world's most powerful autism organization and the main enemy of the movement, and his resignation from his attempts to serve as a moderating influence contributed to reforms that have begun to soften its most contentious practices [44].

A journalist based in Washington, DC has found that a story in which he "outed" and explained himself as a member of the autistic community has led to opportunities to explain autism and disability politics in neurodiversity-affirming ways, a warm reception that demonstrates the growing public interest in autism rights and acceptance (Garcia, Chapter 17).

Morénike Giwa Onaiwu (Chapter 18) describes the principles of and her experience in editing the first anthology of autistic people of color, which in part through its publication by AWN further demonstrates the neurodiversity movement's intersectional autism advocacy [45], amid the broader autism community and media that often implicitly associate autism with whiteness [46].

Part III: Entering the Establishment?

At the present time in which autism acceptance continues to reach new heights, the neurodiversity movement has edged closer to the autism establishment, although the current status looks uncertain. A couple of current examples from the U.K. illustrate this point. In Chapter 19, Craine tells the story of how, following endorsement of the Autism/Neurodiversity

Manifesto by the Labour Party's finance minister, Neurodiversity Labour was launched in February 2019. This organization, led by people with neurodivergences such as autism, ADHD, dyslexia, and dyspraxia, fights discrimination against neurodivergent people within the Labour Party and society. In addition, the National Autistic Taskforce (Murray, Chapter 20) seeks to help implement the U.K.'s principled but hardly enforced legislation such as the Autism Act 2009, which has provisions for the needs of autistic adults. This autistic-led taskforce prioritizes minimally verbal autistic people with high support needs. It grew out of the National Autism Project, which provides access to government consultations and contacts that could help achieve its aims. If the broader autism community, public, and levers of power attain a critical mass of understanding and support for the neurodiversity framework and movement, autistic people will lead advocacy for control of our own affairs.

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