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Neurodiversity and the Field of Speech Language Pathology: A Literary Review of the History, Common Practices, and Misconceptions

Wren Anne Repko
University of Northern Iowa

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NEURODIVERSITY AND THE FIELD OF SPEECH LANGUAGE PATHOLOGY: A LITERARY REVIEW OF

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Wren Anne Repko

University of Northern Iowa

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Approved by:

Dr. Ken Bleile, Honors Thesis Advisor

Dr. Jessica Moon Asa, Director, University Honors Program

Abstract

Neurodiversity is a new and emerging topic within the field of communication sciences and disorders. This literature review describes what neurodiversity is alongside part of the history of neurodiversity, and then turns and looks at neurodiversity and neurodiverse-affirming care in the field of speech language pathology. This literature review also suggests an area of possible future research looking at undergraduate and graduate students' views of neurodiversity.

Introduction

Neurodiversity is a recent topic that many health related fields have begun to pay attention to. It encompasses the idea that there is no one singular brain but instead a wide range of variation of brains with different strengths and weaknesses. It encompasses all people and works to affirm that there is a wide range of brains that function differently. Neurodivergence is then used to describe those whose brains function differently from cultural and societal standards such as with autism. The neurodiversity movement works to affirm that many people's brains may be different from the standards of normal, however they are still people and their neurodivergence cannot be taken out or separated without removing who they are.

Speech language pathologists work with a neurodiverse clientele and have just begun to understand some of the ways neurodivergence may show relating to speech and language. With this has come a new focus and understanding of neurodiverse-affirming care and what that means for the populations speech language pathologists work with. By applying neurodiverse-affirming care speech language pathologists have to question how they provide speech and language services in order to ensure they provide the best possible care within standards of evidence based practice.

This literature review gives a definition of neurodiversity alongside connected terms, looks at some of the history of neurodiversity, looks at some of the research into neurodiversity and autism, and applies neurodiversity to the field of speech language pathology. By doing so it also takes a look at one practice connected to the field, applied behavior analysis, and why it is

not neurodiversity-affirming. This literature review also gives a framework of what neurodiverse affirming care should look like.

Literary Review

What is Neurodiversity?

Neurodiversity is the idea that everyone's brain functions differently. The essential concept is that there is a wide range of variation in how people function cognitively, each person has a different brain that may function similarly to others or differ greatly from the majority, and there is no one single right way of thinking or learning (Constantino, 2018; Baumer & Frueh, 2021). Neurodiversity emphasizes natural variation within the brain and recognizes the unique skills and experiences of neurodivergent people. Being neurodivergent is the idea that a person's brain may function differently, processing information differently from cultural or societal norms of functioning– or, as Constantino puts it someone who is neurodivergent possesses "a minority neurology or one that deviates from the norm" (Constantino, 2018). A neurodivergent person is seen as differing from the typical or the neurotypical, majority neurology (Constantino, 2018). Often the term neurodivergent is used when referring to autism though it includes a variety of other diagnoses such as attention-deficit/hyperactivity disorder, dyslexia, tourette syndrome, traumatic brain injury alongside many other neurotypes (Gaddy & Crow, 2023). Being neurodivergent is simply having a differing brain from the majority neurology.

The neurodiversity movement emerged in the late 1990s (Jaarsma & Welin, 2012; Constantino, 2018). It is commonly credited as having its start with Judy Singer in her bachelor's thesis "Odd People In: The Birth of A Community Amongst People on the 'Autistic Spectrum'"

(Jaarsma & Welin, 2012). Judy Singer coined the term neurodiversity and it is the first time the term appeared in a text. However, even before Judy Singer's thesis Jim Sinclair in 1993 wrote an essay, "Don't Mourn for Us". In this essay while he does not use the term neurodiversity he gives his argument that autism is not an "appendage" or something that can be removed, but instead is "a way of being" (Sinclair, 1993). It is a part of a person that cannot be separated out. The neurodiversity movement has since evolved with the rise of the internet that created platforms for neurodivergent people to connect with each other (Gaddy & Crow, 2023). Neurodiversity has become a large area of study that is prevalent in many fields such as sociology (Leveto, 2018), social justice (Kirby, 2021), and speech-language pathology (Santhanam, 2023; Yu & Sterponi, 2023) alongside many more fields. Each field has their own views on neurodiversity and how it affects a person; alongside how the field personally works with neurodiversity.

Models for Disability

With the increase in understanding neurodiversity there has come a focus on moving away from ideas of impairment-focused treatments, where there is a focus on finding a cure or preventing neurological differences, to instead focus on a model that looks at the social and cultural surroundings of a person (Yu & Sterponi, 2023). This represents a shift away from a medical model, which is focused on treating a perceived deficit or impairment (Constantino, 2018; Yu & Sterponi, 2023). This model often is the default way many think of disability today and it is often used in both medical research and in other areas of research as well. The medical model often sees neurodivergence as something that needs treatment due to it being abnormal (Constantino, 2018). This leads to a focus of treating neurodivergence as something that needs

to be treated as it is a difference in neurological function from what is culturally considered typical (Gaddy & Crow, 2023). This model is often seen as being at odds with the neurodiversity movement due to the model being focused on curing what are seen as impairments.

Neurodiversity fits better within a social model, which looks at neurodivergence not as something wrong but instead as something that is affected by the environment around a person. This looks at neurodiversity through a cultural lens. A social model "conceptualizes disability as contextually situated, rather than biologically given, and as a condition that lies at the intersection of individual and society" (Constantino, 2018). A social model makes a distinction between disability and impairment, impairment being the condition itself and disability being related to cultural surroundings– that is, what the impairment prevents someone from doing due to social practices around them (Camarata, 2022; Yu & Sterponi, 2023). This focuses on making accommodations for disability rather than looking for a fix (Gaddy & Crow, 2023). This fits well with the World Health Organization's International Classification of Functioning, Disability and Health, also known as WHO's ICF, which focuses on how "functioning and disability of an individual occurs in a context" (World Health Organization, 2001). WHO's ICF works as a framework to contextualize how an impairment can affect a person by looking at environmental factors (World Health Organization, 2001). This model also works to have it known that the disabled person should have an active role in their own care and be able to have their own autonomy and agency (Gaddy & Crow, 2023). The social model and WHO's ICF work well with neurodiversity due to how both push for disability to be viewed through a cultural lens. Neurodivergence is viewed not as something wrong with a person but instead something that is a difference to the cultural environment around them.

Rather than a cure for neurodivergence being considered instead the question being asked is what accommodations may be needed.

Autism and Neurodiversity

Much of the research surrounding neurodiversity explores autism. A major focus has been on making changes in diagnostic criteria (Thurm & Swedo, 2012). Advocates have spoken out about neurodiversity and their own experiences (Singer, 1998) or have talked about the care they have received in regards to their autism (Santhanam & Hewitt, 2021). The neurodiversity movement looks towards autism not as something that can be separated out from a person, but instead a natural variation of human neurology (Gaddy & Crow, 2023). This has caused some debate between the usage of person-first language. Many autistic people have expressed they prefer identity-first language rather than person-first language due to autism being a large portion of their identity, something that if taken out would no longer make them themselves. This has been emphasized by a number of autistic advocates, "'Person with autism' suggests that there is a normal person trapped behind the autism. It carries with it the idea that a person is somehow separable from autism" (Jaarsma & Welin, 2011). Identity-first allows the person to express autism as something that is intrinsically part of their identity rather than something that can be removed (Gaddy & Crow, 2023; Watson & Constantino, 2022). By using person with autism, many autistic people have felt that it separates their autism which is a part of their own personal identity from them. However, some people within the Autistic community do prefer person-first language, it depends on the person's own preferences.

One of the many topics brought up when discussing autism is the idea of theory of mind and the concept of the double empathy problem. The idea of autistic people lacking a "theory of mind," that they are unable to realize other people have thoughts, ideas, wants, and beliefs, was a common conception for many early writings (DeThorne, 2020; Gernsbacher & Yergeau, 2019). This idea is still present to this day, however, more recent research has shown that this is not the case. In 2012, Dr. Damian Milton published an article which gave an explanation of what he termed as "the double empathy problem." In this paper he highlights the idea that empathy is bidirectional. With this an autistic person and a non-autistic person may struggle to empathize with each other due to their different lived experiences with the world (Milton, 2012; Gaddy & Crow, 2023; DeThorne, 2020). The double empathy problem at its core is that an autistic person and a non-autistic person may struggle to empathize and relate to each other not due to a lack of theory of mind but rather due to the difference in how they experience the world. Autistic people do not lack empathy like the theory of mind framework suggests, but instead have distinct different ways of thinking and communicating that can lead to misunderstandings and a view that autistic people lack empathy when communicating with neurotypical people.

The evolving language surrounding how people talk about autism has been a leading topic in neurodiversity discussions, such as the terminology of high/low functioning. Instead of using high or low functioning autism, many autistic people prefer describing a person's specific strengths and what access needs they may have in certain contexts (Gaddy & Crow, 2023). By describing the person's specific strengths and the person's difficulties, it can give complete and accurate information about that individual's needs.

Speech Language Pathology and Neurodiversity

Speech language pathology works with a variety of diagnoses across the lifespan alongside a wide variety of neurodiverse clients. When speaking about neurodiversity in speech language pathology, autism is often the first topic to come up. Within speech language pathology there has been a newer focus on how to do neurodiversity-affirming care. With this comes the debates of what should be correct practice to ensure the best possible care. Evidence-based practice, or the integration of clinical expertise, evidence such as research, and client and caregiver perspective, is used to determine the best course of action to provide high quality therapy (ASHA n.d.-a). In order to have neurodiversity-affirming care a clinician has to ensure they provide client-centered care, where the client and their family/caregivers are able to make choices that put the unique needs of the client first (Gaddy & Crow, 2023). This also means ensuring culturally competent services and pursuing cultural responsiveness by understanding that disability and autism both have their own cultures (Agaronnik et al., 2019). An approach to intervention should not be one-size-fits-all, but instead focus on identifying challenges a person may be experiencing and then working to build support and services based on the individual's strengths (Watson & Constantino, 2022). Clinicians should also recognize possible communication differences, value client autonomy, respect multimodal communication, and provide support towards the individual to achieve goals that are meaningful to them (Gaddy & Crow, 2023). With this there is no one specific therapeutic method but instead a set of principles, guiding goals, evaluations, and methods during therapy. Instead of focusing on presenting as neurotypical by encouraging conformity or compliance,

Speech Language Pathologists should focus on providing a framework or tool box for clients to communicate.

A new focus on understanding how certain brains may function differently in relation to learning language has become an area of study for some speech-language pathologists. This led to the realization of a second, distinct language acquisition style known as "gestalt" language development. This language development is a different style of language learning that begins with larger chunks of language, rather than the standard of children learning speech by beginning with single words and then progressing to multiple word utterances (Blanc et al., 2023). By studying this form of language acquisition it has led to a better understanding of there being more than one way children can learn language.

A common therapy method that has been criticized by neurodiversity advocates is applied behavior analysis (ABA). This therapy method has been commonly used with autistic people and has often been criticized for attempting to train autistic children to be more neurotypical (Volkers, 2020; Watson & Constantino, 2022). Many autistic people have said their own experiences with ABA is negative and teaches more about conforming to neurotypical standards. By working towards compliance it also ignores part of evidence based practice, looking at the client perspective. ABA ignores the child's autonomy by teaching them to 'mask' a natural part of themselves (Watson & Constantino, 2022). By forcing a child to mask a part of themselves it often leads to negative habits, since they are taught to ignore signals from their body, that make it so autistic children can appear to conform to neurotypical standards at the cost of masking a part of who they are.

Neurodiverse-affirming care goes hand in hand with the evidence-based process and cultural responsiveness and works to affirm all neurotypes, including neurotypical, by providing meaningful support to an individual and understanding that not every person will respond the same way to therapy methods. Neurodiverse-affirming care works to not force conformity to a neurotypical standard and allows for and respects multimodal communication such as augmentative and alternative communication (AAC). Neurodiverse-affirming care does not only have to be applied to autism but can also be applied to all parts of neurodiversity. At its center, neurodiverse-affirming care for speech language pathology is working with an individual to give them a tool box for communication that will help build on their strengths and recognize their personal challenges.

Conclusion

Neurodiversity is an emerging topic within the field of speech language pathology. By understanding the ideas behind neurodiversity speech language pathologists are able to provide better care to neurodivergent individuals. Speech language pathologists can understand more about the individuals they work with and provide better services by understanding topics such as the double empathy problem. Identity first language is often preferred by many autistic individuals however clinicians should ask what a person prefers. Neurodiverse-affirming care is a framework that works to emphasize client perspectives within evidence based practice and gives clinicians a guiding framework for how to provide the best possible services for both neurodivergent and neurotypical individuals. The application of this framework ensures client autonomy and agency alongside providing a toolbox for speech and language that will work to build off of their personal strengths.

Possible Future Research

In the future, a research study could see how students working towards becoming speech-language pathologists understand neurodiversity through interviews and surveys. This could give some context to how or if neurodiversity is covered during coursework for communication sciences and disorder students. When informally talking to some peers in both undergraduate and graduate courses, a few noted that while they had heard of neurodiversity and had some understanding of it, they did not know much about neurodiverse-affirming care. Having a study that looks at how neurodiversity is covered at both an undergraduate and graduate level alongside students understanding of neurodiversity could bring help to see how neurodiversity has made its way into the field, whether neurodiverse-affirming practices are taught or if it is learned while out in the field. This could also help with understanding student perspectives on neurodiversity as they move through education and see if there is a shift in understanding as a student continues coursework.

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