



2023

Yayınevi: İKSAD Yayınları

A NEW PARADIGM: NEURODIVERSITY APPROACH TO AUTISM

AHI EVRAN 3rd INTERNATIONAL CONFERENCE ON SCIENTIFIC RESEARCH

Yazarlar: Esra MACAROĞLU AKGÜL

A NEW PARADIGM: NEURODIVERSITY APPROACH TO AUTISM

Esra Macaroğlu Akgül

Fatih Sultan Mehmet Vakıf University, Vocational School, İstanbul, Türkiye.

ORCID ID: <https://orcid.org/0000-0001-6897-538X>

ABSTRACT

The paper describes autism in the first step and includes discussions about metaphors related to its definitions. There are several metaphors ranging from “being a disease” to “being an alien”. Having a relationship with someone with autism is determinative in choosing among these metaphors. For people who were neither autistics nor having a relative with autism “autism as a disease” metaphor will be in action, on the other hand for people with either autism or having a relative with autism “autism as neurological diversity-neurodiversity” metaphor will be valid. Although there are different metaphors, social communication disorder is the common issue for all definitions. Other symptoms of autism may be listed as very limited language development, lack of learning with imitating, playing with toys in different ways and lack of or limited eye contact. His/her limited communication is due to delayed or no language development mostly. Different approaches to definition of autism rely on culture also. The paper discusses what neurodiversity approach to autism is and how culture is effective in how society describes and reflects to people with autism.

Keywords: autism, neurodiversity, culture

INTRODUCTION

“If you know one autistic person, you know one autistic person.” This sentence is clearly explaining the uniqueness of each individual with autism. It is not always easy to list common characteristics of autism for every individual. Autism is a very complex situation having still no definite definition. Recent literature reports different definitions reflecting different approaches to autism. Schizophrenic psychosis is the first conceptual description of autism. Based on the latest developments in understanding clinical, neurofunctional and genetic aspects of conceptual and practical definitions of autism has been modified by researchers (Barthélemy & Bonnet-Brilhault, 2016). This paper examines the latest two approaches: conventional medical approach and neurodiversity approach to autism. Paper also discusses the definitions and attitudes towards autism in both perspectives. In the conventional medical approach, autism is defined as a neurodevelopmental disorder diagnosed with lack of social communication and repetitive and restricted behaviors and interest (Lai et al., 2014; Rea et al., 2019). The conventional medical approach focuses on deficits. On the other hand, Pellicano and Houting (2022) explain three difficulties with the conventional medical approach to autism: an overfocus on deficits, an overwhelming emphasis on the individual as opposed to their social context and a narrowness of perspective. They also argue about the necessity of paradigm shift and introduce neurodiversity approach as an alternate paradigm. Based on the knowledge about human brain and mind, it can be said that the number of ways in which brain and mind structurally and functionally develop may vary as the number we may not be able to count. Neurodiversity stems from this broad diversity. The basic of neurodiversity paradigm is its focus on the strengths of all diverse people, like autism and underlines neurotypical is not normal or superior to neurodiverse (Pellicano & den Houting, 2022). Within the framework of different paradigms, metaphors about autism may change from “being a disease” to “being an alien”. If people were not autistic or do not have an autistic relative, they have a desire to use “autism as a disease” metaphor, parallel to conventional medical paradigm, on the other side, autistic or have an autistic relative choose to use “autism as neurological diversity” metaphor for autism, parallel to neurodiversity paradigm. Although there are different metaphors, social communication disorder is the common issue for all definitions. Other symptoms of autism may be listed as very limited language development, lack of learning with imitating, playing with toys in different ways and lack of or limited eye contact. His/her limited communication is due to delayed or no language development mostly.

Societies choose paradigm according to culture they live through. Normal or neurotypical is defined by the culture. How normal or neurotypical was defined shape how autism is defined and being reacted.

RESEARCH AND FINDINGS

The paper discusses how culture of the society influences people's perspectives about and attitudes towards individuals with special needs, more specifically autistic individuals. People's choices related to conventional medical approach or neurodiversity approach would be influenced with the culture. Major research questions discussed in this paper are as follows.

- **How culture shapes parenting in case of having and raising an autistic child?**
- How is autism handled by different paradigms?

Therefore, this section examines the influential effects of culture on family first and neurodiversity and autism second.

Family and Culture

Individuals' beliefs, values, and behavior development are shaped with both culture and family. For a child with special needs, family is the major actor both for participating to society and school. There will be no education without family support. Systems approach which accepts that experiences affecting one member of the family will affect all in the family. More specifically, for a parent having a child with autism, what child experiences in school or society affects siblings and parents. More specifically, social exclusion faced by autistic individual, leads parents of the individual emotional failure. Attitudes towards people with autism may change from country to country and different countries may hold different perspectives about autism. The case in Korea may be a clear example to this. More clearly, in Korea, when a person is married and gave birth to a child, people start calling that person not with his or her first name but call him or her as the mother or father of Z (the child). Additionally, parents' success depends on how their child does in school. In other words, child's level of success determines parents' success in social life. While success in school may level the parents as excellent, failure may cause the opposite. When failure comes in school, it may be parents' fault. Based on this cultural input, it is easy to guess how people think about or perceive you if you have a child with special needs. Most of the man dominant cultures, having an autistic child may be labelled as "shameful" and parents and specifically mothers may mostly be blamed for this (Kim, 2012). Losing support from husband or family is the reflection of cultural influence in society. This may leave mothers lonely with the child and the case of autism. Türkiye is in a similar situation with Korea and there is a big problem in cultural and social acceptance of autistic people. Similarly, when a mother gave birth to a special needs child, almost all husbands and their families would blame on mothers. In a clearer expression, raising a child is perceived as women's responsibility and duty in man-dominant cultures in general. Everybody knows that an autistic child needs more attention and care. The amount of support needed for child would sometimes overload the father and man may leave his child and family with no support. On the other hand, women has no chance to leave the child because of giving birth. It is difficult to understand when society

appreciates the man if he is still around the child. These examples also explain how people's identity and family structure are permanently shaped with the culture. Change the culture by immigrating to another country may be an alternative for many families with an autistic child. They may prefer going through a culture in which almost opposite perceptions about the autistic child and the mother take place like United States or Canada. In these countries, very powerful public support will take place lack of family or fathers' support. Moreover, with this powerful public support, mothers will no more be asking help for their children because people around them will start asking what they can do for the child. Kim (2012) also reports that in countries like US or Canada, for special needs people or autistic ones, support services in schools and community are very accessible. Canada and Korea would be a good example to underline cultural influence on both people with special needs and their families. This cultural difference underlines that "child is not something to be fixed, culture and social environment need to be fixed according to the child's needs". In sum, in neurodiversity approach to autism, "normality" is a cultural construction and being neurodivergent means to be outside of this construct, out of cognitive 'normal'. The approach also helps us to understand that there is no "correct" neurodevelopment. Neurotypical does not mean correct. We can say that neurodivergent development might be privileged as neurotypical ones. The neurodiversity paradigm includes all autistic and neurodivergent people even if they need the highest and most complex support. In some studies, it might be misinterpreted such as only including high functioning individuals.

More specifically, cultural factors are influential in diagnosis of autism. Symptoms in autism might be expressed, recognized, interpreted, and reported according to cultural norms. What is typical is defined by cultural norms, and culture specific definition of parenting determines how parents will afford, access and accept services related to autism. Again, cultural norms shaping individuals' identity also shape their actions towards and communications through autistic people. The neurodiversity paradigm promotes autism acceptance, urging autistic people and others to embrace autism as an inherent and integral part of an autistic person's identity and experience of the world.

Neurodiversity and Autism

Disability or diversity? Focusing on deficits requires to use disability, on the other hand focusing on capacities and strengths requires to use diversity. Diversity was used in 1990's first (Oswal, 2020). For autistic people, analytical thinking, logical reasoning, problem-solving, ability to retain information for a longer period of time with details, being technology-driven and highly focused may be mentioned among the strengths of autistic individuals. Neurodiversity is closely aligned with the social model of disability. Any 'disability' is not best understood as the result of an individual's unique characteristics, but rather it is understood because of an environment that does not effectively accommodate those characteristics. Being disabled and other forms of

human diversity, like ethnicity or gender may similarly result in social power inequalities and disadvantage, effecting society's attitudes and actions (Clouder et al., 2020). As explained in the introduction part, neurodiversity approach focusses on strengths and capabilities rather than deficits. On the other hand, it is undeniable that without a supportive culture and awareness of neurodiversity, professionals and other parts of society will continue to focus on deficits. Knowing that neurodiversity approach requires to involve autistic people and their allies directly in the research process, through participatory, codesigned and coproduced research, for the purpose of increasing the awareness, professionals and researchers in the multidisciplinary areas need to start working with autistic person himself rather than working with their relatives or primary care givers. Very simply, the more we learn from the person, the more we understand the situation.

CONCLUSION

Based on the culture of the society, individuals in different countries hold different perspectives about people with special needs, more specifically autistic people. Findings from literature display that cultural factors are influential in expressing, recognizing, interpreting, and reporting of symptoms in autism. "Neurotypical" or "normal" is defined by cultural norms and culture specific definition of parenting also describes how parents will afford, access, and accept services related to autism. Cultural norms identifying the "normal" shape individuals' identity also. Additionally, norms also shape society's actions towards and communications through autistic people. The important point here is to believe that it is not the child to be fixed, it is culture and social environment need to be fixed. The paper answers the following questions.

- How culture shapes parenting in case of having and raising an autistic child?
- How is autism handled by different paradigms?

Although emotional status of parents throughout the world are similar, there are cultural differences in parenting. For example, man dominating cultures perceive parents unsuccessful if they have an autistic child or a child with special needs and if the child fails in school. Culture leads parents to focus on deficits of the child. Focusing on deficits is a part of conventional medical approach, in which autism is defined as a disorder or disease. In contrary, cultural structures leading parents to focus on strengths will not blame on parents because of child's situation and failure in school. Focusing on strengths is a part of neurodiversity approach. When conventional medical approach is in action, like parents, teachers and other professionals focus on deficits also. Autistic child is perceived as someone to be fixed and normalized. Both parents and the child feel failed. When neurodiversity approach is in action, autistic child is perceived as

someone having strengths in some specific areas and success would be the result if professionals may use their strengths. Both parents and child feel successful. Finally, culture shapes family's and society's perceptions and attitudes towards autistic child. There needs to be a paradigm shift, from medical one to neurodiversity. This shift is necessary for both parents and autistic child's well being.

REFERENCES

- Barthélémy, C., & Bonnet-Brilhault, F. (2016). Autism. In *Neuroscience in the 21st Century: From Basic to Clinical, Second Edition*. https://doi.org/10.1007/978-1-4939-3474-4_91
- Clouder, L., Karakus, M., Cinotti, A., Ferreyra, M. V., Fierros, G. A., & Rojo, P. (2020). Neurodiversity in higher education: a narrative synthesis. *Higher Education*, 80(4), 757–778. <https://doi.org/10.1007/s10734-020-00513-6>
- Kim, H. U. (2012). Autism across cultures: Rethinking autism. *Disability and Society*. <https://doi.org/10.1080/09687599.2012.659463>
- Lai, M. C., Lombardo, M. V., & Baron-Cohen, S. (2014). Autism. *The Lancet*. [https://doi.org/10.1016/S0140-6736\(13\)61539-1](https://doi.org/10.1016/S0140-6736(13)61539-1)
- Oswal, N. (2020). Human resources role in redefining the workplace diversity. *Año*, 36, 876–891.
- Pellicano, E., & den Houting, J. (2022). Annual Research Review: Shifting from 'normal science' to neurodiversity in autism science. In *Journal of Child Psychology and Psychiatry and Allied Disciplines* (Vol. 63, Issue 4). <https://doi.org/10.1111/jcpp.13534>
- Rea, H., LaMotte, K., & Burrell, T. L. (2019). What is autism spectrum disorder? In *Handbook of Parent-Child Interaction Therapy for Children on the Autism Spectrum*. https://doi.org/10.1007/978-3-030-03213-5_1