

Impact of Healthcare on Autism and Targets for Future Improvement

Yixi Wu

College of Social and Behavioral Science, University of Utah, Salt Lake City, 84112, USA

Abstract. Autism spectrum disorder is a developmental disorder that can cause abnormalities in social behavior, language development, and more. In recent years, neurodiversity has viewed autism as a part of identity, represented as a difference between people rather than a disorder that requires treatment. While the debate about autism has not stopped, as society becomes more widely aware of and concerned about autism, more and more people are beginning to leave misconceptions behind and consider this diverse drama in the context of health care and how to help them. The health care system should recognize the challenges and injustices faced by autistic individuals, understand the complications and other social difficulties that they may face, and make enhancements and improvements to the health care system based on their needs. At all ages, autistic people face different challenges and have different needs, this paper takes a chronological view of the needs of autistic people from early childhood to old age, and how the healthcare system can be enhanced to cater to these needs and better provide help and support to autistic people.

Keywords: autism, healthcare system, neurodiversity model.

1. Introduction

Autism is a developmental disorder that can affect people throughout their lives, it reflects neurodiversity that affects the way people see things, feel things, and do things. Dr. Marissa Diener discusses autism under the neurodiversity model and contrasts how this differs from earlier medical models. From a neurodiversity perspective, diversity is welcomed, autistic children are valuable, they have many strengths that are needed, and society needs to adapt to them and make some changes to help remove some of the barriers for autistic individuals (Diener, 2023). This view is widely recognized by experts and is attuned to the feelings and perceptions of autistic individuals. Autism is one of the key components of self-perception for some people who don't see it as a condition that needs to be treated and don't want to eliminate it, which goes right against the early medical model. The medical model suggests that autism needs to be prevented and treated and that the disorder needs to be eliminated while society does not need to make any changes to it.

The recognition of the neurodiversity model and the growing awareness of autism reflects the community's concern for the autism community and its willingness to make changes for them, which are very much needed by autistic individuals. Compared to neurotypical people, autistic adults face high risks to their physical and mental health, and they need more help with screening and treatment for their other illnesses (Nuwer, 2020). The healthcare system has a lot to offer autistic individuals and families, for example, more and more early screenings for autism are becoming partially covered by insurance, and many educational and support programs for the physical health and behavioral development of autistic children are beginning to be expanded to include adults, some programs for the lives and development of autistic individuals are staffed with general physicians knowledgeable about autism-specific issues who provide medical care for autistic individuals within the program, and so on. However, there are still some problems with healthcare for autistic individuals. For instance, many autistic individuals are still exacerbated by a lack of regular medical checkups, many resist hospitalization because they are uncomfortable with the environment of hospitals and consultations, and some older autistic people are not being treated because they do not have enough doctors who know enough about autism, all of which are areas that need to be improved. The purpose of this paper is to discuss, in chronological order, the issues faced by autistic people from childhood to old age, and the challenges and directions for enhancement in the healthcare system.

2. Early Childhood

2.1. Current Status of Health Care for Autistic Children

Although autism is a lifelong disorder, early detection, and intervention can greatly increase the effectiveness of treatment and allow autistic children to better develop their strengths. However, nowadays, many children's conditions are not diagnosed promptly and thus do not receive timely intervention, so much of their developmental potential is not realized on time. Now in the U.S., autism is diagnosed at an average age of four and a half, while the optimal age for diagnosis is two and a half, which is a full two years later (Carbone, 2023). Early diagnosis of autism is a complex matter, requiring a lot of money and time for support, as well as interdisciplinary screening. Dr. Carbone, as a pediatrician, summarizes how autism can be diagnosed at an early stage, starting with the parents recognizing in time some signs of abnormality in their child, then bringing the child to a specialist for communication and exchange of information, and then sending the child for a systematic screening and evaluation of the child in the form of a questionnaire (Carbone, 2023). Fortunately, there are now areas where insurance laws have expanded autism coverage, such as Utah's newest autism insurance law, which removes restrictions on age and duration of coverage and promotes early screening and diagnosis of autism (“Utah State-regulated Insurance Coverage”, 2023).

2.2. Improving the Early Childhood Health Care System

Autistic children need more medical help, and the reality is that autistic children are four times more likely than the general population to not have access to medical help (Access to Comprehensive Health Care, 2023). On the one hand, autistic children may be less likely to interact with other people show less physical discomfort, and are likely to hide actual physical problems if they don't get regular medical checkups and close attention. When an autistic child visits the doctor, he or she may be very uncomfortable in the hospital environment. For example, the sound of the dentist drilling, the harsh lights in the hallways, etc. Most hospitals don't notice this and don't make some slight adjustments to the hospital setup based on the neurodiversity model to accommodate the preferences and needs of autistic children. This can lead to many children being intimidated to go to the doctor, plus they sometimes don't realize the importance of disclosing their condition, which can make the process more complicated and difficult (Doherty, 2020). On the other hand, early intervention for young children requires ongoing, stable financial and time support. Many early interventions, such as Applied Behavioral Therapy (ABA), Occupational Therapy (OT), etc., require that the child be sent to a specialized agency or specialist for several years, and many families give up on early interventions because they can't afford them, which greatly reduces the likelihood of the child's developmental potential being realized.

3. Middle Childhood and Adolescence

3.1. Challenges Faced by Autistic Adolescents

Autistic adolescents also face several difficulties in accessing medical care, resulting in them not receiving timely medical help much of the time. Autistic adolescents often report that going to the hospital is very difficult, so they are very resistant to the hospital environment and to going to the hospital to treat their physical ailments. They indicate that difficulties in accessing medical care begin with seeking help; they find it difficult to take the initiative to express their situation face-to-face, and they are more accustomed to communicating by email or text message; they are fearful of the hospital environment, where they feel they have no autonomy but have to wait to be accommodated, and they feel anxious because they do not know what is going to happen next (Day, 2019). These suggestions from autistic teens illustrate that healthcare should make some accommodations for autistic individuals and help them get comfortable with their visit experience so that they don't delay the progression of their condition to avoid more serious consequences. Autistic individuals have these

experiences because they are neurodiverse, it's not their fault, and it can't be changed, so sometimes healthcare needs to have adaptations.

3.2. Healthcare System Enhancement Goals

Adolescence is one of the most important turning points in a person's life, and during this time, autistic adolescents face many changes in physical development, emotional changes, academic changes, and so on. Therefore, at this stage, healthcare needs to provide them with a lot of psychological support to alleviate the maladjustment they may experience in coping with these changes. Adolescents on the spectrum are at very high risk of developing mental health problems, and they may be chronically depressed or even experience suicidal thoughts. However, they have little access to psychological assistance, and they are unaware of any healthcare system that can deal with the psychological problems of autistic adolescents, and there are no appropriate mental health clinic services for autistic adolescents (Cervantes et al., 2023). Therefore, it is also important to improve the health care system to address the psychological problems of autistic youths and provide them with the help they can get.

4. Emerging Adulthood

4.1. The Current Situation of Autistic Young Adults

When autistic people graduate from high school and are about to enter adulthood, they have to deal with a major transition in their lives during this formative stage. Once upon a time, they lived with their parents and had programs that helped them in school, but from this point on, they were going to have to live more and more independently. Fortunately, transitioning to adulthood for autistic people and their families isn't without help, either in school or in the health care system, unlike in the adolescent years, people need to be on their own, and proactive, in seeking help at this stage (Ashkenazy, 2013). Health Care Transitions (HCT) is a comprehensive healthcare coverage program for autistic individuals transitioning from adolescence to adulthood, but the program only serves about 20% of the target group at this time, and many people don't know what's available to them, and some don't even know it exists (Cheak-Zamora, 2015).

4.2. Society's Response to Autistic Young Adults

The attitude and state of the caregivers of autistic individuals are also very important to the process of healthcare at this stage. For example, many caregivers are concerned that they will lose their custody in the HCT process and will be anxious that they will not be able to provide support to their child (Cheak-Zamora, 2015). In Dr. Anne Kirby's study of the differences between parents and children's perspectives on the transition to adulthood for autistic adolescents, they found that parental choices and expectations have a significant impact on children and that transparent communication between parents and society, children, and society, and parents and children can increase the well-being of the family and the mental health of the child (Kirby, 2023). So, it is important for the health care system to not only provide help to autistic individuals but also to do a better job of reaching out to the families of autistic people and educating them about what the health system can do and how they should properly help their children and promote their psychological and physical well-being.

5. Adulthood and Aging

5.1. Challenges Faced by Autistic People in Middle Age and Old Age

Family care and support are very important to autistic individuals, however, as people reach middle age and old age, they receive less and less help from their families and they experience many unprecedented difficulties as a result (D'Astous, 2023). Autistic older adults are more likely than their peers to have physical and mental disorders, yet they are often unable to receive treatment due to a lack of knowledge about autism on the part of their primary care physicians (Nuwer, 2020).

5.2. Improvements that Should be Made to the Health Care System

To help autistic adults and older people living alone enhance their lives, it is essential to improve the comprehensiveness and accessibility of social healthcare. Firstly, the health care system should increase the training of general practitioners in autism and familiarize them with the use of psychotropic and other medications, so that they are better able to see autistic people. Hospitals should also make the visit as comfortable as possible for neurodiverse people, for example, by making appointments by email or on their website, turning corridor lights to a warm yellow color if permitted, and explaining in detail the process of the visit and the tests they will have to undergo and what they will be going through to reduce their anxiety. Furthermore, health care should reach out to foster homes for autistic seniors and increase the level of care there, on the one hand by training primary care physicians in autism and, on the other hand, by providing regular health care assistance to seniors living alone and in autism centers.

6. Conclusion

In summary, healthcare for autistic people should cover their whole lives, providing them with appropriate and comprehensive support according to the neurodiversity model. It's important to not just polish policies to better help them, but also provide them with accommodation in real life. For instance, early screening for autism should be popularized in schools, and early intervention should be more often included in insurance coverage so that more children can be allowed to develop their strengths and potential; social education on autism should be generalized and educated for professionals, to enhance the understanding of autism among healthcare workers and people in the community, providing better medical assistance to autistic adults; the accessibility to medical services should be improved, to make it more comfortable for autistic people to seek medical assistance. Healthcare is an integral part of development throughout the lifespan of autism and needs to continually evolve toward the goal that neurotypicality and neurodiversity are comfortable together.

References

- [1] Ashkenazy, E. (2013). Navigating college: A handbook on self advocacy written for autistic students from autistic adults.
- [2] Accessing comprehensive health care. Autism Speaks. (n.d.).
- [3] <https://www.autismspeaks.org/advocacy-priorities-accessing-comprehensive-health-care>
- [4] Carbone, P. (2023, August 1). Module 2 [Autism in Early Childhood]. Autism Across the Lifespan Canvas Course. https://utah.instructure.com/courses/876126/pages/week-3-pediatrics-and-healthcare?module_item_id=20491435
- [5] Cervantes, P. E., Conlon, G. R., Seag, D. E., Feder, M., Lang, Q., Meril, S., Baroni, A., Li, A., Hoagwood, K. E., & Horwitz, S. M. (2023). Mental health service availability for autistic youth in New York City: An examination of the developmental disability and mental health service systems. *Autism: The International Journal of Research and Practice*, 27(3), 704–713. <https://doi.org/10.1177/13623613221112202>
- [6] Cheak-Zamora, N. C., & Teti, M. (2015). “You think it’s hard now... It gets much harder for our children”: Youth with autism and their caregiver’s perspectives of health care transition services. *Autism*, 19(8), 992-1001.
- [7] Day, J. (2019). Autism & Healthcare. YouTube. Retrieved August 1, 2023, from https://www.youtube.com/watch?v=IgzrIIM_k48&t=193s.
- [8] Diener, M. (2023, July 31). Module 1 [Introduction to Course and Autism]. Autism Across the Lifespan Canvas Course. https://utah.instructure.com/courses/876126/pages/week-2-neurodiversity?module_item_id=20491430
- [9] D'Astous, V. (2023, August 2). Module 5 [Autism in Adulthood and Aging]. Autism Across the Lifespan Canvas Course. https://utah.instructure.com/courses/876126/pages/week-11-aging-and-later-life?module_item_id=20491465
- [10] Doherty, M., Neilson, S. D., O'Sullivan, J. D., Carravallah, L., Johnson, M., Cullen, W., &

- [18] Gallagher, L. (2020). Barriers to healthcare for autistic adults: Consequences & policy implications. A cross-sectional study. MedRxiv, 2020-04.
- [19] Kirby, A. (2023, August 2). Module 4 [Autism in Emerging Adulthood]. Autism Across the
- [20] Lifespan Canvas Course. https://utah.instructure.com/courses/876126/pages/week-9-family-support?module_item_id=20491456
- [21] Nuwer, R. (2020, March 18). Growing old with autism. Spectrum.
- [22] <https://www.spectrumnews.org/features/deep-dive/growing-old-with-autism/>
- [23] Utah State-regulated insurance coverage. Autism Speaks. (n.d.).
- [24] <https://www.autismspeaks.org/utah-state-regulated-insurance-coverage>