



## **NASET’s Autism Spectrum Disorder Series**

# **Lifespan Services for those Affected with Autism Spectrum Disorder**

**By Lisa Kwapis**

This issue of **NASET’s Autism Spectrum Disorder series** was written by Lisa Kwapis from Florida International University. Autism Spectrum Disorder (ASD) Lifespan service is a topic that is fast approaching the forefront of ASD related research in the 21<sup>st</sup> century. Although this topic is difficult to gather information due to the lack of research available, many feel it is necessary. According to the U.S. Department of Health and Human Services. “An Increasing number of previously undiagnosed adults are being identified.” These eluded Adults with ASD and those who have aged out of their formal educational training years are “having difficulties with employment, social relationships, housing and functioning independently”, and continue to need supportive services. In this article, the following topics will be addressed: traditional understanding of autism spectrum disorder, challenges faced in adulthood, what is being done, and a conclusion statement

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### **Abstract**

Autism Spectrum Disorder (ASD) Lifespan service is a topic that is fast approaching the forefront of ASD related research in the 21<sup>st</sup> century. Although this topic is difficult to gather information due to the lack of research available, many feel it is necessary. According to the U.S. Department of Health and Human Services. “An Increasing number of previously undiagnosed adults are being identified.” These eluded Adults with ASD and those who have aged out of their formal educational training years are “having difficulties with employment, social relationships, housing and functioning independently”, and continue to need supportive services. In this article, the following topics will be addressed: traditional understanding of autism spectrum disorder, challenges faced in adulthood, what is being done, and a conclusion statement

## **Lifespan Services for those affected with Autism Spectrum Disorder**

Traditionally Autism was thought of as an early Childhood disease with little focus on progress towards a happy and fulfilling life. Services were generally provided from a professional standpoint i.e. pediatrician recommendations, specialist and school based teams. In the recent past, it has been determined that “early intervention plans can help increase the likelihood of better outcomes in adulthood.” (hhs.gov strategic plan 2013q.6). However not until the IDEA laws were implemented in 1975 were the rights of individuals with disabilities rights even considered. Only 40+ years ago were strategic plans put into place to aid those with ASD. At best these programs are based for children, leaving many now adults unprepared for the physical, emotional, social and financial demands of adulthood. Today research needs to be addressed and expanded to include Lifespan services for those affected by Autism Spectrum Disorder.

### **Challenges of Adulthood**

According to APA by the numbers database, “26 percent of young adults on the autism spectrum who receive no services during their early 20’s to help them find a job, continue their education or live more independently... \$1.4million is the lifetime cost of supporting an individual with autism spectrum disorder, and \$461 billion is the projected cost of caring for all people with autism spectrum disorder in the US by 2025. If effective interventions, treatments, and services do not become widely available, according to a study in Autism Spectrum Developmental disorders...this is a conservative estimate - the cost could reach \$1 trillion if autism diagnoses continue to rise as they have in recent years, and there are approximately 50,000 people with Autism who turn 18 each year and thus begin aging out of support services.” When services become too difficult to obtain many family members accept the responsibility and management themselves. Without any formal training or knowledge these well intended family members often find great challenges when trying to find employment for adults with ASD. A UN report estimates 80% of adults with autism are unemployed (World Autism Awareness Day 2015). “The types of jobs available are limited in range, and average rate of pay is not adequate to support independent living. Another particularly challenging area is co-occurring mental health conditions, declining impairments as well as discovering new ways to participate and contribute in communities, and new opportunities for achieving health and well-being”.

([hhs.gov/publications/strategic-plan/2013/#q6](https://www.hhs.gov/publications/strategic-plan/2013/#q6)). Without these basic needs of contentment,

happiness, and life satisfaction many health conditions such as depression can arise. In a cross-sectional study on the prevalence of selected clinical problems in older adults with autism and Intellectual disability. “The study estimates of self-injurious, disruptive and destructive behavior were almost double in adults with ASD and ID. The finding of this study revealed the urgent need for research on the nature and treatment of severe behavior problems in the rapidly increasing population of older adults with ASD, and suggest the importance of developing policies that expand our capacity to care for these individuals” across their Lifespan and to provide services for those affected with Autism Spectrum Disorder.

<https://www.ncbi.nlm.nih.gov/pubmed/24066979>.

### **What’s Being Done**

In 2007 the above findings caught the attention of the world. Delegates of the United Nations who took notice and established World Autism Awareness day starting on April 2, 2008 in which. “Members of the UN expressed deep concern regarding the prevalence rates of autism throughout the world and the need to address the long-term outcomes for children, families and communities.”. The Assembly acknowledged and guarantees the rights of Persons with Disabilities to “Live in dignity, strive for a fulfilling life in the community, and be self-reliant economically in adulthood”. ([www.apa.org/international/pi/2015/06/autism-spectrum.aspx](http://www.apa.org/international/pi/2015/06/autism-spectrum.aspx) ). Following suit, the (2009 IACC Strategic Plan) “emphasized the need for research on individual-level interventions to improve outcomes for adults with ASD. Which call for research performed in real-world settings that focus on outcomes related to quality of life, and target the social environment and not just the individual. Focusing on topics such as community housing, life transitions, employment, and services/supports for older adults with ASD

<https://iacc.hhs.gov/publications/strategic-plan/2013/#q6>.

Additionally the Global Autism Public Health (GAPH) an Autism Speaks advocacy organization has been working on developing systematic and sustainable solutions to enhance global awareness, public health policies, training, service delivery and research (Wallace et al.,2012) and has partnered with over 20 countries on six continents to form collaborations among government officials, health care industries and families to identify community priorities, develop strategic plans, reduce social stigma and plan public health care infrastructure”. In September 2014, the National Institute of Mental Health has provided \$7.9 million in funding for 12 research grants that provide real world model services for effectively treating and servicing

each age setting in the Life span of people with ASD.”

([https://iacc.hhs.gov/publications/strategic-plan/2013/#q6.](https://iacc.hhs.gov/publications/strategic-plan/2013/#q6) ) This ever increasing span of adults with ASD has established a drive in practiced based research outside of the traditional formal educational years, and has demonstrated progress towards the health and human service strategic plans Aspirational Goal that “All people with ASD will have the opportunity to lead self-determined lives in the community of their choice through school, work, community participation, meaningful relationships, and access to necessary and individual services and supports.”

## **Conclusion**

Improving participation and achieving a self-satisfying and happy life for those impacted by Autism Spectrum Disorder is on the rise but continues to require further research. “Most of a typical lifespan is spent in adulthood. However, this is the stage of life that is still the least understood in those with ASD.” [https://iacc.hhs.gov/publications/strategic-plan/2013/#q6.](https://iacc.hhs.gov/publications/strategic-plan/2013/#q6) According to Miraj U.Desai “There is a humanistic revolution happening, Guided by the philosophy of “People's health in people's hands,” Two key phrases in this movement are task-shifting and scaling-up. Task-shifting is quite literally shifting the task of care beyond specialists to everyday members of society; scaling-up is increasing the availability of effective care to match overall need.” Research must continue passed the traditional education system and a few organizations, it must become a goal of society to incorporate all the abilities of those adults with ASD into an entire untapped work force. Considering all the unique and special qualities that can be contributed to society, an unconventional and moral approach must be implemented. Thus, breaking down walls that prevent Life-span services for adults with ASD to achieve the American dream of independence.

## References

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By the Numbers A look at autism

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What Does the Future Hold, Particularly for Adults?

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New Grants Funds Cross-Lifespan Services Research for Autism Spectrum Disorder

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Humanistic Revolutions: The Case of Sangath and India By: Miraj U. Desai, M.A., Fordham University

<http://indigenoupsych.org/Members/Desai,%20Miraj%20U/Humanistic%20Revolutions.pdf>

## About the Author

**Lisa Kwapis Johannes** is a hard-working professional dimensional teacher. While working as an InD teacher at Santaluces High School in Lantana Fl. She is pursuing her master's degree with a specialty in autism at Florida International University. She has dedicated her career to becoming an advocate for seniors, students and diverse groups in need of recognition. In 2009 Lisa developed a grassroots program "Meadowedge Social Club" an all-inclusive program in Barnegat NJ that continues to offer encouragement, experience, and exposure to new opportunities for people with special needs. It is her hope to develop an additional program which takes the concept of building a fulfilling life to fruition and solely employ people with special needs in Dog Services. Lisa strives to build a successful career that allows her to use her creative talents to aid in the empowerment of herself and those in need of assistance, through self-accomplishments. In her free time she enjoys traveling, and spending time with her children, family and friends.