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3 Title: Transition to Independent Living for Individuals with Autism Spectrum Disorder
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5 Introduced by: Brent Oldham for the Medical Student Section
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7 Original Authors: Sean Jones, Aayush Mittal, Jaya Parulekar, and Samantha Rea
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9 Referred to: Reference Committee E
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11 House Action: **APPROVED AS AMENDED**
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13
14 Whereas, the Centers for Disease Control (CDC) indicate that the prevalence of autism spectrum
15 disorder (ASD) has risen from 1 in 150 in 2002 to 1 in 59 in 2014, with an estimated 50,000 children with ASD
16 turning 18 years old every year^{1,2,3}, and
17

18 Whereas, a paralleled prevalence increase is expected to occur within the next 12 years for those
19 who are entering adulthood, representing a crisis for clinicians providing services to adults after completing
20 high school⁴, and
21

22 Whereas, there were 20,595 children with ASD last year in Michigan schools⁵, and
23

24 Whereas, the U.S. Department of Health and Human Services requires schools to provide special
25 education and related services, including transition services, for students with ASD who meet the eligibility
26 criteria under the Individuals with Disabilities Education Act³, and
27

28 Whereas, transitioning into adulthood is a formal process within U.S. school systems that helps
29 students at the age of 16 make plans for life after high school, such as college, employment, vocational
30 training, independent living and adult disability services^{2,3,6}, and
31

32 Whereas, many individuals with ASD still require considerable assistance with communication,
33 community living, and social skills, which can carry on into adulthood as they attempt to find housing and
34 services to live independently^{1,4,6,7}, and
35

36 Whereas, compared to other psychiatric conditions, adults with ASD have higher rates of anxiety and
37 depression and are more likely to live with parents or other family members, some taking up to 10 years to
38 achieve independent living compared to the general population^{8,9}, and
39

40 Whereas, children with ASD fared worse than their peers with other types of disabilities in several
41 measures of post-high school outcomes such as living in low-income households or living in households
42 that receive household food benefits¹⁰, and
43

44 Whereas, individuals with personalized living arrangements have improved well-being compared to
45 those in congregate homes with no choice over whom they lived with⁸, and
46

47 Whereas, the 2014 Autism CARES Act specifies the importance of comprehensive approaches to
48 transitioning from existing school-based services to those services available during adulthood, including
49 community-based integrated residential services, housing, and transportation², and
50

51 Whereas, while elements specified in the Autism CARES Act focus on improving outcomes through
52 the transition to adulthood, there are currently no federally funded service programs focusing solely on the
53 transition to adulthood among youth with ASD, with only a handful of research studies targeting this
54 population being funded², and

55 Whereas, under Sections 1915(b)/(c) of the Social Security Act and Medicaid, states can develop
56 home and community based (HCBS) waivers to meet the needs of a particular target group that requires
57 long-term care services and supports in their home or community, rather than in an institutional
58 setting^{11,12,13,14}, and

59
60 Whereas, Medicaid requires that all HCBS settings allow full access to the greater community, and
61 the individuals utilizing this program be given independence in making life choices¹⁵, and

62
63 Whereas, while the state of Michigan offers two HCBS waivers through Medicaid that can be applied
64 to care coordination for ASD, MI Children's Waiver Program and MI Habilitation Supports, only the former
65 specifically targets specialty services for children with ASD and only until the age of 17^{16,17}, and

66
67 Whereas, due to a lack of focused, coordinated, well-funded services, many youth and young adults
68 with ASD remain dependent on family members, pediatric service providers, and public programs, such as
69 Medicaid, rather than gaining the independence necessary to enter adulthood³; therefore be it

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71 RESOLVED: That MSMS supports improved resources for transition to independent living for
72 individuals with Autism Spectrum Disorder.

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74
75 WAYS AND MEANS COMMITTEE FISCAL NOTE: \$1,000 or more for costs related to the adoption of new or
76 revised MSMS or AMA policy.

Relevant MSMS Policy: None

Relevant AMA Policy: None

¹ Centers for Disease Control and Prevention. "CDC estimates 1 in 68 children has been identified with autism spectrum disorder" 2014.

² U.S. Department of Health and Human Services "Young Adults and Transitioning Youth with Autism Spectrum Disorder" Report to Congress. 2017.

³ Roux, A.M., et. al "Postsecondary employment experiences among young adults with an autism spectrum disorder" J Am Acad Child Adolesc Psychiatry. 2013. 52(9): 931-9

⁴ Sarris, M. "Leaving the pediatrician: charting the medical transition of youth with autism" Kennedy Krieger Institute: Interactive Autism Network. 2015.

⁵ Michigan Department of Health and Human Services "Autism Awareness, Education, and Resources" 2018.

⁶ Roux, Anne M., Shattuck, Paul T., Rast, Jessica E., Rava, Julianna A., and Anderson, Kristy, A. National Autism Indicators Report: Transition into Young Adulthood. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, 2015

⁷ Shattuck, P.T., et. al :Postsecondary education and employment among youth with an autism spectrum disorder - Pediatrics. 2012. 129(6):1042-9

⁸ Quality of life: a case-controlled long-term follow-up study, comparing young high-functioning adults with autism spectrum disorders with adults with other psychiatric disorders diagnosed in childhood. Barneveld PS, Swaab H, Fagel S, van Engeland H, de Sonneville LM. Compr Psychiatry. 2014 Feb;55(2):302-10.

⁹ "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. Nancy C Cheak-Zamora, Michelle Teti. National Autistic Society. December 11, 2014

¹⁰ Activities of daily living and transition to community living for adults with intellectual disabilities. King E, et al. Scand J Occup Ther. 2017. Sep;24(5):357-365.

¹¹ Home and Community Based Services. Center for Medicare and Medicaid Services. January 2014.

¹² Centers for Medicare & Medicaid Services. "Home & Community-Based Services 1915(c)." Medicaid.gov, 2019.

¹³ Roux, Anne M., Shattuck, Paul T., Rast, Jessica E., Rava, Julianna A., and Anderson, Kristy, A. National Autism Indicators Report: Transition into Young Adulthood. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, 2015

¹⁴ Bal, Vanessa Hus, et al. "Daily Living Skills in Individuals with Autism Spectrum Disorder from 2 to 21 Years of Age." Autism, vol. 19, no. 7, 2015, pp. 774-784., doi:10.1177/1362361315575840.

¹⁵ Summary of Key Provisions of the Home and Community-Based Services (HCBS) Settings Final Rule (CMS 2249-F/2296-F). Center for Medicare and Medicaid Services. January 2014.

¹⁶ Centers for Medicare & Medicaid Services. "Michigan Waiver Factsheet." Medicaid.gov, 2019.

¹⁷ Disabled and Elderly Health Program Group, Centers for Medicare and Medicaid Based Services. Children's Waiver Program 1915(b)(4) Extended. June 2018.