

Healthcare providers' discussions regarding transportation and driving with autistic and non-autistic patients: A brief report

Emma Sartin (✉ sartine@chop.edu)

CHOP: The Children's Hospital of Philadelphia <https://orcid.org/0000-0002-0609-8235>

Rachel K. Myers

CHOP: The Children's Hospital of Philadelphia

Christina G. Labows

CHOP: The Children's Hospital of Philadelphia

Kristina B. Metzger

CHOP: The Children's Hospital of Philadelphia

Meghan E. Carey

CHOP: The Children's Hospital of Philadelphia

Benjamin E. Yerys

CHOP: The Children's Hospital of Philadelphia

Catherine C. McDonald

University of Pennsylvania School of Nursing

Cynthia J. Mollen

CHOP: The Children's Hospital of Philadelphia

Allison E. Curry

CHOP: The Children's Hospital of Philadelphia

Research Article

Keywords: autism spectrum disorder, transportation, driving, healthcare providers

Posted Date: June 2nd, 2021

DOI: <https://doi.org/10.21203/rs.3.rs-538546/v1>

License:  This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Version of Record: A version of this preprint was published at Journal of Autism and Developmental Disorders on December 1st, 2021. See the published version at <https://doi.org/10.1007/s10803-021->

05372-3.

Abstract

Objective: To characterize healthcare and behavioral service providers' transportation-related discussions with their autistic and non-autistic patients.

Method: Seventy-eight providers completed a cross-sectional survey assessing their transportation discussions with patients. We used Mann-Whitney U tests and chi-square tests to compare differences in provider reports by patient diagnosis.

Results: Compared with one in two providers who reported they discuss transportation with non-autistic patients, only one in five have these conversations with their autistic patients. Few (8%) providers felt prepared to assess driving readiness in autistic patients, yet only a quarter refer patients elsewhere.

Conclusion: There is a critical need to develop resources for use in medical settings to effectively support autistic adolescents' independence and mobility as they transition into adulthood.

Introduction

Transitioning from adolescence to adulthood is often a challenge for autistic individuals. A substantial proportion of autistic young adults feel disconnected from both work and education, more so than peers with other disabilities (Roux, Shattuck, Rast, Rava, & Anderson, 2015). One barrier to autistic young adults participating in activities outside of the home is a lack of transportation (Geller & Greenberg, 2009; Kersten, Coxon, Lee, & Wilson, 2020). Being able to travel without relying on others for rides or for companionship/supervision is associated with better psychosocial, health, and employment outcomes for both autistic and non-autistic populations (Ellaway, Macintyre, Hiscock, & Kearns, 2003; Zalewska, Migliore, & Butterworth, 2016). Autistic individuals cite multiple barriers to or difficulties with independently driving, using public transportation, and/or walking (Deka, Feeley, & Lubin, 2016; Roux, Rast, Anderson, & Shattuck, 2017). Importantly, with support, many autistic individuals may be able to overcome these barriers and safely travel independently. For example, a one-on-one travel training intervention improved autistic young adults' competencies in skills needed to independently use public transportation (Pfeiffer, Sell, & Bevans, 2020). Additionally, one-third of autistic youth without an intellectual disability (ID) acquire a driver's license by the time they are 21 years-old, and newly licensed autistic drivers have similar to lower per-driver rates of crashes and moving violations than their non-autistic peers (Curry et al., 2021; Curry et al., 2018). Thus, there is a need to develop and implement supports that empower autistic individuals to balance autonomy and safety in transportation to facilitate better life outcomes following their transition to adulthood.

Health and behavioral service providers may be uniquely poised to provide resources or counsel and assist families as they make transportation-related decisions. Several studies have reported parents, adolescents, and providers themselves consider the teen's primary care physician a resource for information about transportation topics, and in particular, independent driving (Ford et al., 2016; Gaw et al., 2020; Mirman, Goodman, Friedrich, & Ford, 2018). However, a recent survey found only 62% of primary

care physicians were comfortable counseling their patients on driving (Gaw et al., 2020). Further, autistic individuals may experience unique challenges during provider-patient interactions (e.g., communication and sensory difficulties; Duker, Kim, Pomponio, Mosqueda, & Pfeiffer, 2019). To our knowledge, no research has examined providers' transportation-related discussions with their autistic patients, and how these discussions may differ from those they have with their non-autistic patients.

Thus, we conducted a cross-sectional survey with providers to characterize their perspectives regarding transportation discussions with their patients. Specifically, we aimed to evaluate the extent to which providers who see both autistic and non-autistic patients have transportation-related discussions, how old the patient is when these discussions occur, whether providers believe they can assess patients' readiness to drive, and if they routinely refer patients to other providers for driving issues.

Methods

We conducted a cross-sectional survey of pediatric health and behavioral service providers between March and April 2019. We recruited participants via email from two sources: (1) relevant departments and practices across the [BLINDED TEXT] pediatric healthcare network located in [BLINDED TEXT] and (2) providers at [BLINDED TEXT] Autism Centers for Excellence (*ACE) locations, which deliver services to autistic individuals in northeast [BLINDED TEXT]. We distributed a total of 829 recruitment emails; 144 providers took the survey. For the current analyses, we excluded 9 respondents who did not complete the entire survey or had no direct patient contact. Finally, because our goal was to compare how providers approach discussions with their autistic and non-autistic patients, we limited analyses to the 78 providers who care for both autistic and non-autistic patients. Participation was voluntary; no compensation was provided.

Surveys were administered through [BLINDED TEXT]'s Research Electronic Data Capture (REDCap) portal and designed to be completed in ≤ 10 minutes (Harris et al., 2019, 2009). The survey was informed by young driver research (Anderson, Sosnowy, Kuo, & Shattuck, 2018; Mirman, Curry, Elliott, Long, & Pfeiffer, 2018; Taylor & Henninger, 2015). First, providers answered questions about their practice location, clinical role, and demographic information. Then, providers answered if they deliver care to autistic adolescents without ID, and if so, completed to a series of questions to assess the extent to which providers have discussions with these patients on topics related to transportation. Specifically, providers answered the following questions: (1) With what proportion of your autistic adolescent patients and their families do you discuss topics related to transportation (free text with a valid range of 0-100); (2) At what age do you typically begin to discuss transportation with autistic adolescent patients and their families (free text with valid range between 0-20 years); (3) Thinking of your typical autistic adolescent patient, do you believe that you have adequate knowledge to assess driving readiness (yes/no); and (4) Are there other providers for whom you routinely refer adolescent patients and their families for issues related to independent driving (yes/no)? Providers then answered the same questions for their non-autistic patients.

We used Mann-Whitney U and chi-square tests to compare medians and the proportion of providers endorsing certain answers by patient diagnosis. All analyses were completed using R version 3.6.3 (R Core Team, 2014). This study was approved by the [BLINDED TEXT] Institutional Review Board.

Results

Table 1 presents participant characteristics and demographics. Participants reported having various health care provider roles in several different practice settings, with the majority being attending physicians (54%) and psychologists (23%) practicing in Primary Care (40%) and Child and Adolescent Psychiatry and Behavioral Services (22%). Providers reported having transportation-related discussions with a greater proportion of their non-autistic patients compared with their autistic patients (median [IQR]: 50% of non-autistic patients [26, 90] vs. 20% of autistic patients [3, 50], $p < 0.001$). Providers reported first discussing transportation-related topics with families at a median age of 15, with similar distributions for non-autistic and autistic patients (median [IQR] for non-autistic patients: 15 [15, 16]; for autistic patients: 15 [14, 16]). Only 33% of providers endorsed having adequate knowledge to assess driver readiness among their non-autistic patients, and an even lower percentage, 8%, believed they could assess readiness among their autistic patients ($p < 0.001$). While few providers felt prepared to assess driver readiness, only 26% reported that they routinely refer any of their patients to other providers for issues related to driving independently.

Table 1
Participant Characteristics (N= 78)

	N (%)
Role	42 (54)
Attending Physician	3 (4)
Physician Fellow	18 (23)
Psychologist	4 (5)
Licensed Professional Counselor	1 (1)
Psychiatrist	4 (5)
Nurse Practitioner	6 (8)
Social Worker	
Provider Practice Locations	31 (40)
Primary Care	17 (22)
Child and Adolescent Psychiatry and Behavioral Services	10 (13)
Developmental and Behavioral Pediatrics	7 (9)
Neurology	6 (8)
Adolescent Medicine	6 (8)
[BLINDED] Autism Centers for Excellence	4 (5)
Other	
Sex	63 (81)
Female	15 (19)
Male	
Race/Ethnicity	4 (5)
Hispanic	60 (77)
Non-Hispanic White	6 (8)
Non-Hispanic Black	6 (8)
Non-Hispanic Asian	3 (4)
Not reported	

Note. All percentages are rounded to the nearest whole number.

	<i>N</i> (%)
Age	20 (26)
25–34	24 (31)
35–44	21 (27)
45–54	10 (13)
55–64	2 (3)
65+	1 (1)
Not reported	
Percent of patients that are autistic	59 (76)
≤ 25%	15 (19)
26–50%	4 (5)
≥ 50%	
<i>Note.</i> All percentages are rounded to the nearest whole number.	

Discussion

Healthcare and behavioral service providers may be well positioned to counsel autistic youth and their families as they make transportation-related decisions. To our knowledge, this is the first study to characterize providers' conversations about transportation with their autistic patients. Our survey found that only one in five providers discuss transportation with their autistic patients and that these discussions were not initiated until patients were about 15 years old. Further, while few providers indicated that they possess adequate knowledge to assess driving readiness in autistic patients only a quarter of them refer patients to other providers for driving-related issues.

The Interagency Autism Coordinating Committee recognizes the urgent need for services that improve health and quality of life for autistic individuals as they transition from adolescence to adulthood (Interagency Autism Coordinating Committee, 2020). Autistic young adults who are able to travel independently have better employment, health, and social outcomes than their peers who rely on others for transportation (Zalewska et al., 2016). However, certain core features of autism—including impairment in executive functioning, motor coordination, attention, visual scanning skills, and understanding social cues—may create unique barriers this population must navigate in order to travel independently and safely (Bishop, Biasini, & Stavrinou, 2017; Corbett & Constantine, 2006; Kenworthy, Yerys, Anthony, & Wallace, 2008; Kenworthy, Yerys, Weinblatt, Abrams, & Wallace, 2013; Oliveras-Rentas, Kenworthy, Roberson, Martin, & Wallace, 2012). Thus, there is a critical need to support autistic youth and their

families as they make important transportation-related decisions. Despite this, our findings indicate provider-family discussions around transportation occur less frequently for autistic patients. These differences may stem from other challenges autistic patients reference when interacting with providers during healthcare encounters, including communication and sensory issues (Duker et al., 2019). Further, transportation-related conversations were not typically initiated until patients were around 15 years old, which is later than the American Academy of Pediatrics and American Academy of Family Physicians' recommendation that transition to adulthood planning begin at age 12 (American Academy of Pediatrics & American Academy of Family Physicians, 2011). While more research is needed, initiating transportation conversations earlier in adolescence might provide more time for autistic youth to benefit from access to supports to improve independent mobility, including those built into non-healthcare institutions; for example, a prior survey of autistic adolescents' parents found that including transportation goals in the adolescent's Individual Education Plan substantially increased their odds of becoming a driver (Huang, Kao, Curry, & Durbin, 2012).

Finally, few providers felt adequately prepared to assess their autistic patients' driver readiness. Notably, the majority of surveyed providers practice in Pennsylvania, which requires healthcare providers certify individuals' physical ability to drive before they can obtain a learner's permit. Even more concerning is that—despite the low proportion of providers who felt prepared to assess driving readiness in either patient group—only one in four reported that they routinely refer any of their patients to other providers for driving issues. Thus, there is a critical need for tailored resources and education that can equip medical settings to foster autistic youths' autonomy in transportation, including driving. Based on our findings and previous work, we specifically see the need for resources that: (1) support or facilitate provider-patient discussions about transportation; and (2) equip providers with guidance on whom to refer patients to for expert assessment or guidance (e.g., certified driving rehabilitation specialists).

Our results' generalizability is limited by our use of a convenience sample recruited from an urban region in the northeastern U.S. Additionally, Pennsylvania requires adolescents receive a physical exam before they can obtain a learner's permit. This likely creates a natural prompt for providers to discuss transportation and driving with their patients, and therefore these patient-provider discussions may occur even less frequently in states that do not have this requirement. Despite this, our voluntary survey was able to characterize responses from an array of providers from diverse practice settings and clinical roles.

Declarations

ACKNOWLEDGEMENTS

First, the study team would like to thank our participants for voluntarily completing this survey. Additionally, we would like to acknowledge Drs. Lisa Biggs, Carol Ford, Nate Blum, Annemarie Clarke, Jessica Mirman, Patty Huang, Miriam Monohan, and Julie Lounds Taylor, as well as Rania Mansour, for their contributions to this project and manuscript. This work was supported by the Eunice Kennedy Shriver National Institute of Child Health and Human Development at the National Institutes of Health

Awards R01HD079398 and R01HD096221 (PI: Curry). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. The sponsor had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; or decision to submit the manuscript for publication.

Disclosures:

The authors have no conflicts of interest to disclose.

References

- Anderson, K. A., Sosnowy, C., Kuo, A. A., & Shattuck, P. T. (2018). Transition of individuals with autism to adulthood: A review of qualitative studies. *Pediatrics, 141*, S318–S327.
<https://doi.org/10.1542/peds.2016-43001>
- Bishop, H. J., Biasini, F. J., & Stavrinos, D. (2017). Social and non-social hazard response in drivers with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 47*(4), 905–917.
- Corbett, B. A., & Constantine, L. J. (2006). Autism and attention deficit hyperactivity disorder: assessing attention and response control with the integrated visual and auditory continuous performance test. *Child Neuropsychology, 12*(4–5), 335–348.
- Curry, A.E., Metzger, K. B., Carey, M. E., Sartin, E. B., Huang, P., & Yerys, B. E. (2021). Motor vehicle crashes and traffic violations among autistic adolescent and young adult drivers. *Journal of the American Academy of Child and Adolescent Psychiatry*.
- Curry, Allison E., Yerys, B. E., Huang, P., & Metzger, K. B. (2018). Longitudinal study of driver licensing rates among adolescents and young adults with autism spectrum disorder. *Autism, 22*(4), 479–488.
<https://doi.org/10.1177/1362361317699586>
- Deka, D., Feeley, C., & Lubin, A. (2016). Travel patterns, needs, and barriers of adults with autism spectrum disorder: Report from a survey. *Transportation Research Record, 2542*(1), 9–16.
<https://doi.org/10.3141/2542-02>
- Duker, L. I. S., Kim, H. K. S., Pomponio, A., Mosqueda, L., & Pfeiffer, B. (2019). Examining primary care health encounters for adults with autism spectrum disorder. *American Journal of Occupational Therapy, 73*(5), 7305185030p1-7305185030p11.
- Ellaway, A., Macintyre, S., Hiscock, R., & Kearns, A. (2003). In the driving seat: psychosocial benefits from private motor vehicle transport compared to public transport. *Transportation Research Part F: Traffic Psychology and Behaviour, 6*(3), 217–231.

Ford, C. A., Cheek, C., Culhane, J., Fishman, J., Mathew, L., Salek, E. C., ... Jaccard, J. (2016). Parent and adolescent interest in receiving adolescent health communication information from primary care clinicians. *Journal of Adolescent Health, 59*(2), 154–161.

<https://doi.org/10.1016/j.jadohealth.2016.03.001>

Gaw, C. E., Berthet, E., Curry, A. E., Zonfrillo, M. R., Arbogast, K. B., & Corwin, D. J. (2020). Pediatric health care provider perspectives on injury prevention counseling in acute and primary care settings. *Clinical Pediatrics, 59*(13), 1150–1160. <https://doi.org/10.1177/0009922820941237>

Geller, L. L., & Greenberg, M. (2009). Managing the transition process from high school to college and beyond: Challenges for individuals, families, and society. *Social Work in Mental Health, 8*(1), 92–116.

Harris, P. A., Taylor, R., Minor, B. L., Elliott, V., Fernandez, M., O'Neal, L., ... Duda, S. N. (2019). The REDCap consortium: Building an international community of software platform partners. *Journal of Biomedical Informatics, 95*, 103208.

Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research electronic data capture (REDCap)- A metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics, 42*(2), 377–381.

Huang, P., Kao, T., Curry, A. E., & Durbin, D. R. (2012). Factors associated with driving in teens with autism spectrum disorders. *Journal of Developmental & Behavioral Pediatrics, 33*(1), 70–74.

Interagency Autism Coordinating Committee. (2020). *IACC Strategic Plan for Autism Spectrum Disorder (ASD) 2018-2019 Update*. Retrieved from <http://iacc.hhs.gov/strategic-plan/2019/>

Kenworthy, L., Yerys, B. E., Anthony, L. G., & Wallace, G. L. (2008). Understanding executive control in autism spectrum disorders in the lab and in the real world. *Neuropsychology Review, 18*(4), 320–338.

Kenworthy, L., Yerys, B. E., Weinblatt, R., Abrams, D. N., & Wallace, G. L. (2013). Motor demands impact speed of information processing in autism spectrum disorders. *Neuropsychology, 27*(5), 529.

Kersten, M., Coxon, K., Lee, H., & Wilson, N. J. (2020). Independent community mobility and driving experiences of adults on the autism spectrum: a scoping review. *American Journal of Occupational Therapy, 74*(5), 7405205140p1-7405205140p17.

Mirman, J. H., Curry, A. E., Elliott, M. R., Long, L., & Pfeiffer, M. R. (2018). Can Adolescent Drivers' Motor Vehicle Crash Risk Be Reduced by Pre-Licensure Intervention? *Journal of Adolescent Health*. <https://doi.org/10.1016/j.jadohealth.2017.09.015>

Mirman, J. H., Goodman, E. S., Friedrich, E. A., & Ford, C. A. (2018). Talking with teens about traffic safety: initial feasibility, acceptability, and efficacy of a parent-targeted intervention for primary care settings. *Journal of Safety Research, 66*, 113–120.

Oliveras-Rentas, R. E., Kenworthy, L., Roberson, R. B., Martin, A., & Wallace, G. L. (2012). WISC-IV profile in high-functioning autism spectrum disorders: impaired processing speed is associated with increased autism communication symptoms and decreased adaptive communication abilities. *Journal of Autism and Developmental Disorders*, *42*(5), 655–664.

American Academy of Pediatrics & American Academy of Family Physicians. (2011). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*, 182–200. <https://doi.org/10.1542/peds.2011-0969>

Pfeiffer, B., Sell, A., & Bevans, K. B. (2020). Initial evaluation of a public transportation training program for individuals with intellectual and developmental disabilities: Short report. *Journal of Transport and Health*, *16*, 100813. <https://doi.org/10.1016/j.jth.2019.100813>

Roux, A. M., Rast, J. E., Anderson, K. A., & Shattuck, P. T. (2017). *National autism indicators report: Developmental disability services and outcomes in adulthood*.

Roux, A. M., Shattuck, P. T., Rast, J. E., Rava, J. A., & Anderson, K. A. (2015). *National autism indicators report: Transition into young adulthood*.

Taylor, J. L., & Henninger, N. . (2015). Frequency and correlates of service access among youth with autism transitioning to adulthood. *Journal of Autism and Developmental Disorders*, *45*(1), 179–191. <https://doi.org/10.1007/s10803-014-2203-x>.Frequency

R Core Team. (2014). *R: A language and environment for statistical computing*. Vienna, Austria: R Foundation for Statistical Computing.

Zalewska, A., Migliore, A., & Butterworth, J. (2016). Self-determination, social skills, job search, and transportation: Is there a relationship with employment of young adults with autism? *Journal of Vocational Rehabilitation*, *45*(3), 225–239.