

**THE UNIVERSITY CENTER FOR EXCELLENCE IN
DEVELOPMENTAL DISABILITIES**

DATA REPORT:

**Survey of Primary Care Physicians: Serving Adults with Autism Spectrum
Disorders**

March 2010

**University of Connecticut
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INTRODUCTION

Autism spectrum disorders (ASDs) can be defined as a group of developmental disabilities that cause significant social, communication, and behavioral challenges; ASDs include Asperger syndrome, autistic disorder (classic autism), and pervasive developmental disorder-not otherwise specified (PDD-NOS). Current estimates are that 1 in 110 children in the United States have an ASD. There are no widely accepted prevalence rates for adults with ASD. We do know that the population of adults with ASD is growing in Connecticut and across the nation, yet little is known about this population or the health care services they are receiving; specifically, who is providing health care services for this population. This study focuses on primary care physicians in Connecticut who serve adults with autism spectrum disorders (ASD). The purpose of this study was to assess physician involvement in the care of adults with ASD and to determine health care providers' need for training and support in serving this population.

METHODOLOGY

Procedure: Physicians in Connecticut were contacted by mail to complete a brief survey about serving adults with autism spectrum disorders. Researchers obtained a list of 1580 physicians in CT listed in a WebMd database. The survey was initially mailed to 600 randomly selected physicians from the list in mid-September 2009. Due to a low response rate, the survey

was mailed to all physicians on the list in the beginning of January 2010. Nineteen were “returned to sender” due to inaccurate addresses.

Each physician received a cover letter, survey, and self-addressed, stamped envelope for return of the survey. The cover letter included information on the purpose of the study and instructions for completion. Participants could opt to complete an online version of the study and instructions were provided for this as well. The cover letter also thanked participants who had already completed the study. See Appendix A for a copy of the cover letter.

Data Collection: Surveys were completed both through paper copies and online through Survey Monkey. Only five surveys were completed online. Data collection lasted for approximately five months. The Survey Monkey link was closed at the end of February and any surveys that were returned by mail after February were filed, but not entered into the database. Participation in the survey was completely voluntary, and respondents could skip any questions they did not wish to answer.

Survey: The survey consisted of 14, multiple-choice questions. Three questions allowed participants to choose more than one response option, and four questions provided participants with space for open-ended responses in addition to the response options. The first two questions established the type of population served by the physician, as we were interested in physicians who served adults with autism spectrum disorders. The next eight questions focused on the characteristics of the patients with ASD (living arrangements, typical health needs, employment, age, etc.). The final four questions were about the interest and need for training on caring for adults with ASD and other developmental disabilities. Participants were also given the opportunity to provide their contact information if they were interested in receiving the results of the study or being contacted for additional studies. See Appendix B for a copy of the survey.

Data Management: As surveys were received, contact information from the last page was entered into an Excel spreadsheet and that page was detached and filed separately from the survey. Each paper survey was given an ID number and data was manually entered into SPSS. Reliability was conducted on 24% of the data entries. Mean reliability was 99%. For instances of disagreement, researchers met, reviewed the original data, and agreed on what should be entered.

Data that was collected through Survey Monkey was downloaded into an excel file and then imported into SPSS. Each completed survey was also printed, labeled with an ID number, and filed. Contact information collected through Survey Monkey was entered into the Excel spreadsheet with the other contact information.

Data Analysis: Descriptive statistics (frequencies and percentages) were calculated for the data. Responses to open-ended questions were summarized. The results from the data analysis of the survey are presented in the following results section.

RESULTS

A total of 376 physicians participated in this survey, 30 of whom indicated they did not provide primary medical care for adults. Of the 346 physicians who provide primary care for adults, 139 of them indicated serving adults with ASD.

Population characteristics. The majority of adults with ASD served by physicians in CT are male and between the ages of 18 and 40. The most common medical condition of adults with ASD as reported by physicians is general yearly checkups (32%) and mental health related issues (22%). Approximately 49% live with family; and 36% are employed, while 17% attend school. Adults with ASD are also receiving the following services: mental health (71.9%), job support (43.9%), transportation (43.9%), dental services (38.8%), respite (11.5%) and other (6.5%).

Other responses included home health care/nursing services, housing, case management, employment, and cardiol services. See Table 1 for a complete list of characteristics.

Table 1. Percentage of responses for questions 3-10 (N=139; physicians who serve adults with ASD)

3. Average age	
18-40	71.9
41-50	16.3
51 or older	8.9
4. Sex of the majority of adults with ASD I care for:	
Male	71.6
Female	27.6
5. Most common medical condition:	
Infectious	14.6
Metabolic	13.9
Neurological	2.9
Gastrointestinal	.7
Mental Health	21.9
General Checkups	32.1
Other	4.4
6. Can independently understand and follow recommendations	
Yes	45.3
7. Living arrangements	
Independently	11.5
With family	48.5
In supervised setting	40.0
8. The majority of adults with ASD I care for are attending school	
Yes	17.4
9. The majority of adults with ASD I care for are employed	
Yes	36.3
10. Patients are also receiving these services:	
Mental Health	71.9
Job support	43.9
Dental services	38.8
Transportation	43.9
Respite	11.5
Other	6.5

Training needs. 346 physicians completed questions related to training in caring for adults with ASD. 206 physicians served adults, but indicated none of their patients had ASD. 139 physicians cared for adults with ASD; 113 indicated caring for between one and five adults with

ASD, 18 indicated caring for six to nine, and eight physicians indicated caring for ten or more. The results described here are based on all 346 physicians who care for adults. For a comparison of responses between physicians who do and do not care for adults with ASD, see Table 2. The majority of physicians (64%) have not received training in caring for adults with ASD. For those who did receive training; 18% was during their professional education (medical school), 15% was post-residency CME, and 13% was during residency. The majority of physicians would like more training in caring for adults with ASD (55%) and caring for adults with other developmental disabilities (54%). Some reported disabilities that physicians would like more training on include intellectual disabilities, Down’s syndrome, cerebral palsy, and ADD/ADHD. Preferred modes of training included workshops/conferences (45%), web-based (37%), detailed reading material (33%), and Grand Rounds (26%). A few physicians (3%) indicated other preferred modes of training such as CD/DVD, audio, and courses.

Table 2. Percentage of responses by group (only those who serve adults with ASD, and only those who serve adults, but none with ASD)

	Serve adults with ASD (N=139)	Do not serve adults with ASD (N=206)
11. My training in the care of adults with ASD occurred during (% selected):		
Professional education	23.0	12.5
Residency	19.4	5.9
Post-residency CME	20.1	10.5
N/A Did not receive training	55.4	72.4
12. I would like more training specific to caring for adults with ASD (% yes)	67.2	43.4
13. I would like more training in caring for adults with other DDs (% yes)	63.9	45.4
14. My preferred mode(s) of receiving training include (% selected):		
Workshops/conferences	52.9	38.2
Grand Rounds	28.8	23.0
Web-based	41.7	32.2
Detailed reading material	34.5	30.9
Other	2.2	4.6

CONCLUSION

The results of this survey provide a baseline of data that indicates the small number of physician in this state who are serving adults with autism spectrum disorders, as well as their lack of training to serve this population. Future research is needed to identify the barriers to serving adults with autism spectrum disorders, as well as the perspective of adults with ASD on accessing health care services. Future research should also expand this study to include multiple geographic regions. Finally, the medical field should focus on ways to get physicians the training they need in caring for this population, whether it be through education in medical school or continuing education once in practice.

Appendix A

January 1, 2010

Invitation:

We invite you to complete and return this short questionnaire in the self-addressed, stamped envelope. It should take no longer than five minutes to complete. For your convenience, you may instead complete the survey online by going to www.uconnucdd.org and clicking on the link under the "What's New" heading. The password to access the survey is "ASD." If you have already completed this survey, thank you again for your participation.

The Study:

The University of Connecticut A.J. Pappanikou Center for Excellence in Developmental Disabilities at the UCONN School of Medicine has recently received a Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) grant from the Maternal and Child Health Bureau (MCHB) in order to provide training to graduate students and community service providers on serving those with developmental disabilities including Autism Spectrum Disorders (ASD). As part of this process, we are conducting needs assessments with various provider groups in order to develop training opportunities.

The Disclosure:

There are no identifiable risks from the collection of information for this survey and there are no costs to you. Submission of the survey, either by mail or via the internet, implies consent. Your participation is voluntary and you may refuse to participate and/or discontinue participation at any time without consequence. You may also skip any question that you do not wish to answer. You will not be paid for completing this survey.

The information you provide will be kept confidential to the extent of the law and no one other than the project staff will be allowed access to the information. This information will be stored in locked file cabinets and electronic formats will be password protected in a way that protects your information from anyone other than project staff. At the conclusion of this project, staff may publish their findings (reports can be found at: www.uconnucdd.org). Information from you will be reported in summary format and you will not be identified in any publications or presentations.

Contact Information:

Questions about this survey may be directed to the Principal Investigators, Dr. Mary Beth Bruder, Dr. Gerard Kerins, or Dr. Neil Stein at (860) 679-1500.

Sincerely,

Mary Beth Bruder, Ph.D.
Professor of Pediatrics & Educational Psychology
Director, University of Connecticut A.J. Pappanikou
Center for Excellence in Developmental Disabilities
Education, Research, and Service

Appendix B



University of Connecticut
A.J. Pappanikou Center for Developmental Disabilities

**Survey of Primary Care Physicians: Serving Adults with
Autism Spectrum Disorders**

Directions: We invite you to complete and return this short questionnaire in the self-addressed, stamped envelope. It should take no longer than five minutes to complete. For your convenience, you may instead complete the survey online by going to www.uconnucedd.org and clicking on the link under the "What's New" heading. The password to access the survey is "ASD." If you have already completed this survey, thank you again for your participation.

Unless specified, please choose only one answer.

1. I currently provide primary medical care for adults (18+).
 - Yes
 - No (*please stop here and return the survey in the envelope provided*)

2. The number of adults with Autism Spectrum Disorders (ASD) that I care for is:
 - Zero (*please skip to question 11*)
 - 1 – 5
 - 6 – 9
 - 10 or more

3. The average age of the adults with ASD that I care for is:
 - 18 – 40
 - 41 – 50
 - 51 or older

4. The majority (>50%) of adults with ASD that I care for are:
 - Male
 - Female

5. The **most common** medical condition of adults with ASD that I care for is:
 - Infectious (ear nose and throat, pneumonia, urinary tract infection)
 - Metabolic (thyroid disease, diabetes)
 - Neurological (seizure disorder, stroke)
 - Gastrointestinal (constipation, GERD, celiac disease)
 - Mental health related (depression, anxiety disorders, psychoses)
 - Generally well, just yearly check-ups
 - Other: (please specify) _____

6. The majority of adults with ASD that I care for are able to independently understand and follow my recommendations.
 - Yes
 - No

7. The majority of adults with ASD that I care for predominantly live:
- Independently
 - With family
 - In a supervised setting/group home
8. The majority of adults with ASD that I care for are currently attending school.
- Yes
 - No
9. The majority of adults with ASD that I care for are currently employed.
- Yes
 - No
10. My adult patients with ASD are also receiving the following services: (check all that apply)
- Mental health
 - Job support
 - Dental services
 - Transportation
 - Respite
 - Other: _____
11. My training in the care of adults with ASD occurred during: (check all that apply)
- Professional education (medical school)
 - Residency
 - Post-residency CME
 - N/A I did not receive training
12. I would like more training specific to caring for adults with ASD.
- Yes
 - No
13. I would like more training specific to caring for adults with other developmental disabilities.
- Yes
 - No
- If yes, what disabilities: _____
14. My preferred mode(s) of receiving training include: (check all that apply)
- Workshops/Conferences
 - Grand Rounds
 - Web-based
 - Detailed reading material
 - Other: _____

If you would like to participate in any of our follow-up surveys or receive a copy of our results for this study, please provide your contact information below.

Upon receiving your returned survey, project staff will immediately separate your contact information from your responses. Your contact information will be locked in a file cabinet and password protected in an electronic database. Your survey responses will only be reported as aggregate data and you will not be personally identified in any publications or presentations.

I would like to be contacted for additional studies.

I would like to receive the results of this study.

Name: _____

Practice: _____

Address: _____

Email: _____

Phone: _____

Please return this survey in the provided envelope.

THANK YOU!!!