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Access to Autism Evaluation Appointments With Developmental-Behavioral and Neurodevelopmental Subspecialists

Autism spectrum disorders impact 1 in 110 children in the United States.[1] Early intervention can improve the developmental trajectory of children with autism spectrum disorders,[2] but eligibility and guidance for services can benefit from comprehensive diagnostic medical evaluation from a developmental-behavioral (DB) or neurodevelopmental disabilities (NDD) subspecialist.[1,3,4]

Concerns regarding increasing need and shortage of DB/NDD subspecialists have been raised,[5] but the extent of access barriers to DB/NDD evaluations is unknown. In light of recent expansions of Medicaid and the Children's Health Insurance Programs (CHIP), there is also a need to determine whether DB/NDD subspecialist access is limited by insurance status. Prior studies of insurance-related barriers relied on family reports,[6] which are prone to recall/response biases. The goal of this study was to measure real-life experiences of accessing appointments with DB/NDD subspecialists.[7]

Methods. From April to May 2010, one of us (J.B.) called all DB/NDD subspecialists' offices in the Chicago, Illinois, metropolitan area posing as a mother requesting a new patient appointment for her 4-year-old son. The standardized script, reporting a primary care referral because of symptoms of autism and speech delay, was developed and piloted with input from 2 DB pediatricians and a parent of 2 children with autism. If paperwork was

Table. Appointment Availability, Acceptance of Insurance, and Procedures for Scheduling Appointments at 14 Developmental-Behavioral Pediatrics and Neurodevelopmental Disabilities Subspecialty Physician Clinics

Characteristics	No. (%)	Mean (SD) [Range]
Appointment availability and acceptance of insurance		
Clinic accepts Medicaid/CHIP coverage (n=14)	13 (93)	
Clinic accepts BCBS coverage (n=14)	13 (93)	
Wait time for appointments, Medicaid/CHIP, No. of days (n=11)[a]		85 (56) [18-165]
Wait time for appointments, BCBS, No. of days (n=10)[b]		77 (52) [18-164]
Clinic treats BCBS and Medicaid/CHIP the same	12 (86)	
Clinic disclosed preferential treatment for Medicaid/CHIP (n=14)	0	
Clinic disclosed preferential treatment for BCBS (n=14)	2 (14)	
Insurance type was requested by the clinic (n=14)	8 (57)	
Insurance type was the first question asked (n=14)	4 (29)	
Clinic accepts only cash (n=14)	1 (7)	
Total cash payment amount, $ (n=1)		1100
Cash payment amount needed on day of appointment, $ (n=1)		275
Wait time for cash-only appointment, No. of days (n=1)		9
Appointment scheduling procedures (n=14)		
Duration of the call, No. of minutes		8 (4) [4-17]
Length of time on hold during the call, No. of minutes		2 (4) [0-11]
Written screening form required prior to scheduling appointment	5 (36)	
Written screening form requested to bring to appointment	1 (7)	
Verbal screening required prior to scheduling appointment	1 (7)	
In-person screening required prior to scheduling appointment[c]	2 (14)	
Referral forms are requested (but not required to schedule)	7 (50)	
Referral forms are required prior to scheduling appointment	0	
Insurance/Medicaid ID number required prior to scheduling	1 (7)	
Child's social security number required prior to scheduling	1 (7)	
Details pertaining to written screening forms (n=6)		
Length of written screen form, No. of questions		158 (58) [71-242]
Method of delivering written screening form		
E-mailed	2 (33)	
Faxed or mailed (for this study, faxes were requested)	3 (50)	
Downloaded off the Internet	1 (7)	

Abbreviations: BCBS, Blue Cross Blue Shield; CHIP, Children's Health Insurance Programs.
[a] Of the 13 clinics that accepted Medicaid/CHIP coverage, 11 gave real or hypothetical appointment times; 2 clinics could not estimate wait time conditional on completing the scheduling procedures.
[b] One clinic scheduler thought the BCBS wait time would be shorter but could not quote a wait time for BCBS without consulting others in the clinic (this case was considered missing BCBS wait time information).
[c] Includes 1 clinic requiring patients to go to the institution's walk-in screening center prior to scheduling an appointment and 1 clinic requiring the patients to be seen by a primary care provider at their institution prior to scheduling an appointment.

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required, the caller asked for an appointment conditional on returning the paperwork the following day. If asked, she reported her son's enrollment in Illinois' combined Medicaid/CHIP program. If insurance information was not requested by the end of the call, the caller confirmed that Medicaid/CHIP was accepted. On all calls, she indicated that she could enroll in Blue Cross Blue Shield, inquiring if that would help in obtaining a sooner appointment. The study was institutional review board approved with a debriefing letter; calls were kept as short as possible and appointments were cancelled immediately.

We developed an exhaustive list and called all DB/NDD clinics in the target counties. Clinics were considered "out of scope" if the practice said they did not see patients with autism concerns (before knowing insurance type). Any referrals to other numbers/clinics were followed up. If multiple sites were scheduled through a single number, the caller asked for the soonest appointment at any site. If a screening/"intake" form was requested, forms were collected via a nondescript e-mail address or local fax number. Descriptive statistics are reported for appointment availability, insurance acceptance, and number of questions/information fields per screening form.

Results. Initially, 30 DB/NDD physicians with 40 unique telephone numbers (ie, clinics) were identified. Of these, 26 were out of scope. The 14 remaining clinics scheduled appointments for 15 physicians, 2 clinics (14%) scheduled appointments for 2 sites, 9 (64%) had a DB subspecialist(s) only, 4 (29%) had an NDD subspecialist(s) only, and 1 had both DB and NDD subspecialists. As depicted in the **Table**, 12 clinics gave the caller appointments and 2 clinics declined to estimate appointment times conditional on next-day completion of the screening process. All clinics accepted both public and private coverage except 1 clinic that rejected both insurances, required $1100 cash payment, and had the shortest wait time (9 days). Two clinics (14%) disclosed preferential treatment (ie, sooner appointments) for private vs public coverage, but only 1 provided an estimate of the shorter wait time. Overall, the mean (SD) wait time was 85 (56) days for Medicaid/CHIP–enrolled children and 77 (56) days for Blue Cross Blue Shield–enrolled children. Of the 14 clinics, 8 (57%) required completion of a clinical screening prior to scheduling appointments. Screening forms averaged 158 questions (range, 71-242 questions).

Comment. In a large metropolitan area with a relatively high density of DB/NDD subspecialists, there was a 3-month average wait time for autism evaluations, regardless of insurance status, as well as screening/intake processes that required high levels of parental health literacy and persistence. Findings signal the need to explore mechanisms for more efficient use of scarce DB/NDD subspecialty resources and for professional consensus regarding the kind of screening that is clinically necessary as a prerequisite for scheduling new patient evaluations.

Joanna Bisgaier, MSW
Dana Levinson, MPH
Diana B. Cutts, MD
Karin V. Rhodes, MD, MS

Author Affiliations: Department of Emergency Medicine, School of Medicine (Dr Rhodes), and School of Social Policy and Practice (Ms Bisgaier and Dr Rhodes), University of Pennsylvania, Philadelphia; Pritzker School of Medicine, University of Chicago, Chicago, Illinois (Ms Levinson); and Department of Pediatrics, Hennepin County Medical Center, Minneapolis, Minnesota (Dr Cutts).

Correspondence: Dr Rhodes, Department of Emergency Medicine and School of Social Policy and Practice, University of Pennsylvania, 3815 Walnut St, Room 201, Philadelphia, PA 19104 (kvr@sp2.upenn.edu).

Author Contributions: *Study concept and design:* Bisgaier, Levinson, Cutts, and Rhodes. *Acquisition of data:* Bisgaier. *Analysis and interpretation of data:* Bisgaier, Levinson, Cutts, and Rhodes. *Drafting of the manuscript:* Bisgaier. *Critical revision of the manuscript for important intellectual content:* Bisgaier, Levinson, Cutts, and Rhodes. *Statistical analysis:* Bisgaier and Rhodes. *Obtained funding:* Rhodes. *Administrative, technical, and material support:* Levinson, Cutts, and Rhodes. *Study supervision:* Rhodes.

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