

Putting Recommendations into Practice: Obtaining Services for Children Recently Diagnosed with ASD

M.A McCarthy, K.S. Branch, L.J. Lawer, L.A. Plummer, and D.S. Mandell,
University of Pennsylvania School of Medicine; Penn/CHOP Center for Autism Research

Background

- Best practice guidelines suggest intensive and specific therapies for children with ASD.
- The extent to which physician recommendations are in line with guidelines is unknown.
- The barriers that parents face in obtaining physician-recommended services are unknown.

Objectives

- Examine physician recommendations to parents of children newly diagnosed with ASD
- Compare services children receive post-diagnosis with physician recommendations and describe associated barriers to obtaining services.

Methods

- Parents completed questionnaires and semi-structured interview ≤8 weeks post-diagnosis.
- Parents' reports of service use and barriers to care were abstracted from interview transcripts
- Diagnosing physician's recommendations were abstracted through chart review.

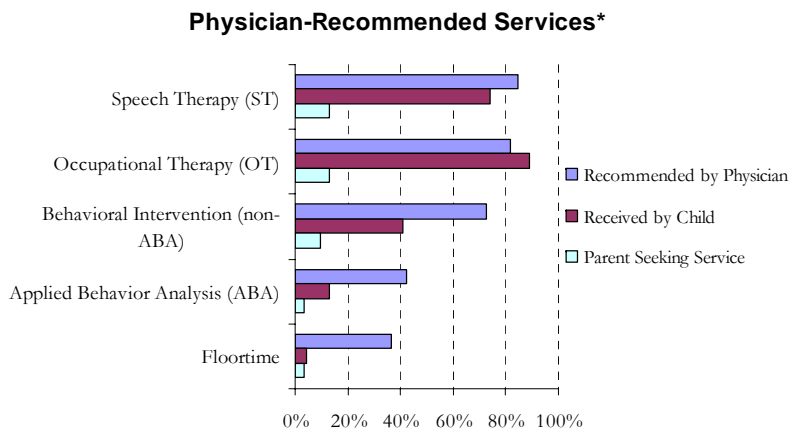
Sample

- 37 parents of children recently diagnosed with ASD at one children's hospital.
- Average age of diagnosed child was 3.4 years
- Mother's average age: 36.1 years
- Father's average age: 38.6 years
- 78% Caucasian, 16% African-American, 5% Hispanic

Parent Description of Access to Service

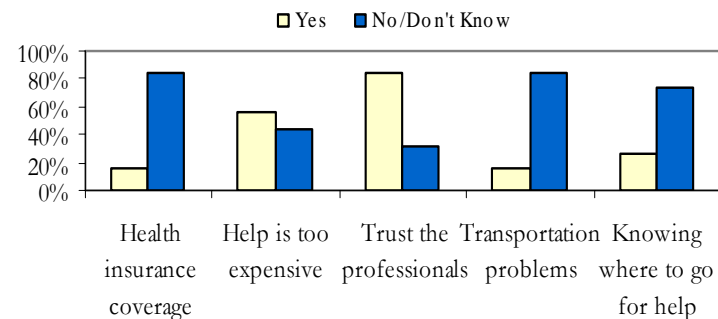
- "...pretty good about giving the very minimal level of service, but they really fought me on everything else... [for] ABA it was 'He's so young he can't handle more than an hour a week or two hours.'... I pushed it up to ten... they never showed up for ten. It was difficult."
- "Dr. also prescribed...wraparound services 20-25 hours a week in the home...and I'm getting no response...When I do actually get a person instead of a voicemail, I hear, 'We don't have anyone who goes to your neighborhood.'"
- "I don't even know what we want. On his evaluation report...it does say 'get a special instructor with a Floortime model.' Like I said, I feel like I need to be an expert...like go... and Google this to find out everything I need to know so I can get the best treatment plan."
- "...finding his services, making sure everything's lined up and everything is okay, and being an advocate for him has been tough."

Quantitative Results



*Charts were not available for 3 children

Barriers to Care



Implications

- Even within the same institution, treatment recommendations post-diagnosis vary. It's not clear what accounts for this variation
- OT and ST are often recommended and accessed through Early Intervention, whereas specific behavioral therapies require additional steps for parents to obtain services.
- Parents of children with autism face difficulties obtaining recommended services. This disparity between recommended and obtained services may be due to:
 - Lack of parent awareness of how to obtain services
 - Lack of qualified providers
 - Other financial or geographic barriers to care