

PS1-13:

Variation in the Incidence and Prevalence of Autism from Multiple Health Systems: Findings from the Mental Health Research Network Autism Registry Study

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Background/Aims: Autism spectrum disorders (ASD) are characterized by impairments in social interaction and communication, as well as restricted, stereotyped interests and behaviors. A recent study found that approximately 1 in 88 children in the U.S. were diagnosed with an ASD and that prevalence varied widely among different demographic groups. The goals of this study were to obtain accurate prevalence and incidence statistics for ASD across several large, diverse health systems and to describe the variation of these statistics across demographic factors. **Methods:** All members within the five participating health systems born between January 1, 1993 and December 31, 2008 with electronic claims, enrollment, or medical record information were included in the study. Information on member demographics and ASD subtypes were collected from earliest available records at each site through the end of December 31, 2010. Individuals with an ASD diagnosis from an ASD specialist or two or more ASD diagnoses from non-specialists were defined as valid cases. **Results:** A preliminary examination of data from one site (N = 1,271,823) found 10,114 individuals <18 years ever diagnosed with an ASD. Of those 10,114 ASD cases, 8,085 met the validation criteria and were included in final analyses. Prevalence of all ASDs in children ≤8 years old was 1.1/1000 in 2001 (1 in 909 children) and increased steadily to 7.1/1000 in 2010 (1 in 141 children). Prevalence specifically for autistic disorder (AD), a more severe subtype, in children ≤8 years old was 0.3/1000 in 2001 and increased to 1.9/1000 in 2010. Similar secular increases were noted for incidence. Prevalence and incidence varied greatly among demographic groups. Prevalence of all ASDs in 2010 was 8.4/1000 among Whites, 7.1/1000 among Blacks, and 10.6/1000 among Asians. Prevalence of ASDs among females was lower than among males in all years (2010 males: 11.2/1000, 2010 females: 2.8/1000). **Conclusions:** This study provides up-to-date prevalence and incidence information from a group of large, diverse, community-based settings. Incidence and prevalence differed across racial groups and sex status. Strong increasing trends in the diagnosis of ASDs in general, as well as the AD subtype, were observed.

Keywords: Autism; Prevalence; Incidence

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PS1-14:

Health-Related Quality of Life in Children with Autism Spectrum Disorders: Findings from the Mental Health Research Network Autism Registry Web Survey

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Background/Aims: Approximately 1 in 88 children in the U.S. is diagnosed with Autism Spectrum Disorder (ASD). ASD is a complex disorder characterized by impairment in social skills, communication, and cognitive and behavioral functioning. In order for policy makers and clinical managers to evaluate new approaches to treating and managing ASD, they need brief comprehensive outcome measures. One approach that could be useful in this context is measurement of health-related quality of life (HR-QOL), which provides a comprehensive picture of health status including an individual's psychosocial, emotional, and physical wellbeing. This comprehensive approach is particularly important in conditions such as ASD that have multiple impacts on a person's health. Few previous studies have examined HR-QOL in persons with ASD, and most of these studies have used small

samples. The purpose of this analysis is to examine HR-QOL in a group of geographically- and racially/ethnically-diverse children with ASD who are enrolled in the Mental Health Research Network (MHRN) Autism Registry. **Methods:** A Web-based survey of parents of children with ASD was implemented at four MHRN Autism Registry sites, including children's HR-QOL, measured by the Pediatric Quality of Life Inventory (PedsQLTM). The PedsQLTM provides an overall score, as well as subscales for important domains including physical health, psychosocial health, emotional functioning, social functioning, and school functioning. **Results:** To date, recruitment letters have been mailed to approximately 8800 parents and 800 surveys have been completed. Preliminary analyses of respondents indicate that HR-QOL is lower in children with ASD compared to national norms. We will present the final results from the survey, which will conclude in November 2012. The presentation will examine the overall scores, scores on subscales, and scores by subgroup (e.g., age, gender, race) and will compare these scores to national norms. **Conclusions:** We successfully implemented a Web-based survey of parents of children with ASD across four MHRN sites. With 800 completed surveys (recruitment will continue through November 2012), this is the largest known population-based survey on children with ASD to date. The current study will help to confirm results from smaller samples and will allow for more refined analyses of subgroups.

Keywords: Autism; Health-Related Quality of Life

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PS1-16:

Directions for Future Patient-Centered and Comparative Effectiveness Research for People with Serious Mental Illness

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Background/Aims: Individuals with serious mental illnesses can experience significant disability, affecting ability to guide and adhere to treatment and navigate systems. Needs for a range of services are common, yet despite recent efforts to improve care quality, persistent challenges blunt or derail reforms. Obstacles include: difficulties changing the focus of care from acute symptom control/relapse prevention to patient-centered/recovery-focused care; constructing coherent, integrated services; coordinating care while managing multiple, fluctuating funding streams; and high staff turnover that produces poor continuity of care. Our goal is to provide guidance for future comparative effectiveness and patient-centered outcomes research (CER, PCOR) to improve individual-level patient-centered outcomes (PCOs). **Methods:** With stakeholders and technical experts, using an iterative consensus approach, we created a definition of what constitutes a care and service delivery intervention, constructed a theoretical model of a learning system to improve quality and coordination of care, developed an analytic framework, and conducted a narrative review to identify research gaps, high leverage points, and key questions for future CER and PCOR. **Results:** (1) We need more patient centered outcomes developed by or in concert with service users. (2) Information regarding the outcomes service users value most and least remains limited. Value-based information is fundamental to patient-centered care and PCOs. (3) Most efforts to improve quality of mental health services have focused on care processes and necessary institutional structures. Links between indicators of process and structure, and PCOs, are nearly non-existent. (4) Few efforts have been made to aggregate PCOs to provide performance feedback at the clinician, organization, or system level; methods and processes are needed. (5) Financing of services is structured in ways that complicate and impede coherent, integrated delivery, and research comparisons. (6) Current CER information is not adequate to produce system change. Complexity theory suggests focusing on organizational culture/climate, supporting employees and promoting high-quality interactions/teamwork. Interactions are the nexus of information processing/sense-making that are necessary in a learning system. **Conclusions:** Health care reform is creating multiple opportunities to exceed current incremental efforts to improve outcomes. Developing learning systems that provide real patient-centered/patient-directed care to individuals with serious mental illnesses should capitalize on these openings. **Keywords:** Serious Mental Illness; Comparative Effectiveness Research; Patient-Centered Outcomes Research

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