Chapter 55

Telehealth-Based Systems for Diagnosis, Management, and Treatment of Autism Spectrum Disorders: Challenges, Opportunities, and Applications

Fiorentina Angjellari-Dajci
Rochester Institute of Technology (RIT), USA

William F. Lawless
Paine College, USA

Nitin Agarwal
University of Arkansas at Little Rock, USA

Ron Oberleitner
Behavior Imaging Solutions, USA

Barbara Coleman
Augusta State University, USA

Masoud Kavoossi
Howard University, USA

ABSTRACT

The prevailing system for diagnosis, treatment, and management of Autism Spectrum Disorders (ASDs) in the US—the in-person service delivery—has been unable to address the increase in the demand for services and societal costs for those served, and the unattained societal benefits for those not diagnosed early enough or not offered early and intensive behavioral interventions. The authors discuss new developments in telehealth for diagnostic evaluation and ASD treatment in the US. They build a theoretical model to capture telehealth system’s potential in reaching ASD screening market equilibrium under the constraint of full utilization of provider hours and other stylized facts. The authors estimate the market demand for ASD screening in the US for year 2011. They present their progress with a case study that focuses on the potential impacts of increased access to care of technology-based telehealth on the Georgia-South Carolina border. The authors use social network analysis to envision the future of telehealth service delivery for ASDs.

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INTRODUCTION

Autism Spectrum Disorders (ASDs) are a group of lifelong neurodevelopmental disabilities characterized by atypical development of verbal and nonverbal communication, impaired reciprocal social interaction and restricted and repetitive patterns of behavior, interests and activities that profoundly affect the way a person comprehends, communicates and relates to others (Mandell & Palmer, 2005). In addition to these core features, a range of other behavior problems are common, such as anxiety, depression, sleeping and eating disturbances, attention issues, temper tantrums, and aggression or self-injury. (Myers & Johnson, 2007) The term ASD has been used to include Pervasive Developmental Disorders classified in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR) under these five diagnostic categories: autistic disorder, Asperger’s disorder, Pervasive Developmental Disorder–Not Otherwise Specified (PDDNOS), Childhood Disintegrative Disorder (CDD) and Rett syndrome (DSM-IV-TR, 2000).

Over the last two decades, ASD prevalence in the US has been on a steady rise. (Centers for Disease Control [CDC], 2011; Individuals with Disabilities Education Act [IDEA], 2011) Currently one in 110 American children carries a diagnosis of ASD. In some states, such as Georgia, this prevalence is higher (1 in 98), and one study found that administrative prevalence in Georgia may underestimate true ASD prevalence and demand for ASD services (Boyle, Van Naarden & Yeargin-Allsopp, 2005). The rise in ASD prevalence has raised significant public health concerns given the shortage of trained specialists in the treatment of ASDs, especially in rural areas.

The increase in ASD prevalence has implications for the annual and lifetime per capita societal costs incurred. For example lifetime societal cost of caring for and treating a person on the autism spectrum in the US has been estimated to be $3.2 million (in 2003 dollars), and about $35 billion for an entire birth cohort of people with ASDs. (Ganz, 2007) Given the increase in ASD prevalence, a revision of these estimates will most likely result in higher societal costs in the US in 2011.

Currently, the in-person service delivery is the prevailing system for diagnosis, treatment and management of ASDs in the US. Such a system has been unable to address: (1) the increasing gap between service delivery supply and demand, (2) the increasing societal costs for those served, and (3) the unattained societal benefits for those not diagnosed early enough or not offered early and intensive behavioral intervention treatments, which have been proven to produce substantial benefits over the long run (Jacobson, Mulick & Green, 1998; Lovaas, 1987; McEachin, Smith & Lovaas, 1993; Ospina et al., 2008).

We argue that telehealth service delivery could be initially introduced as a complementary (additional) delivery system, especially in providing services in rural areas, and gradually gain market share, by becoming a competing system to the in-person delivery due to the several socio-economic benefits it provides for the three main stakeholder groups: the client/caregiver, the provider, and the payer.

The introduction of telehealth service delivery in ASDs could narrow the supply-demand gap and eventually help achieve market equilibrium. In addition, provided that telehealth service delivery meets the effectiveness criteria for early and intensive behavioral interventions (Guralnick, 1998; Ramey & Ramey, 1998), additional clinical and socio-economic benefits are likely to emerge. Such benefits could be monetized along with all other societal benefits and compared to all incurred societal costs for both telehealth and in-person service deliveries. Last, the large-scale implementation of telehealth service delivery in ASDs will most likely require high start up and maintenance costs when compared to the in-person delivery. However, once implementation has reached a large scale, it is also likely to produce cost-savings from economies of scale.