

Systems of Care for Individuals with Autism Spectrum Disorder and Serious Behavioral Disturbance Through the Lifespan

Martin J. Lubetsky, MD^{a,*}, Benjamin L. Handen, PhD, BCBA-D^a,
Michelle Lubetsky, MEd, BCBA^b, John J. McGonigle, PhD^a

KEYWORDS

- Autism • Systems of care • Service delivery • Early intervention
- Department of Developmental and Intellectual Disabilities • Department of Education
- Department of Mental Health/Behavioral Health • Office of Vocational Rehabilitation

KEY POINTS

- Parents request guidance and instruction from professionals after the diagnosis of Autism Spectrum Disorder/Intellectual Disability is confirmed because many complex systems are involved.
- The education system is directed by the Individuals with Disabilities Education Act, including the Individual Education Plan, which must be tailored to fit the needs of the child and adolescent.
- The Intellectual Disability system has supports to assist with the pursuit of waiver funding and individualized services, and to prepare and monitor the Individual Support Plan.
- The Mental Health/Behavioral Health System offers service coordinators to assist with finding resources and individualized services.
- The Medical System is complex and requires providers who are knowledgeable and able to coordinate primary care, dental, vision, nutrition, and other specialists to promote integration into a “medical home model of care.”

INTRODUCTION

Individuals with Autism Spectrum Disorder (ASD) have unique needs, and interventions must be individualized for successful outcomes. It is beneficial to optimize

Disclosure Statement: None (M.J. Lubetsky, J.J. McGonigle, M. Lubetsky); B.L. Handen has received industry research support from Eli Lilly, Bristol Myers Squibb, and Curemark. He also has received research support from Autism Speaks, HRSA, NIA, and NIMH.

^a Department of Psychiatry, Western Psychiatric Institute and Clinic of UPMC, University of Pittsburgh School of Medicine, 3811 O’Hara Street, Pittsburgh, PA 15213, USA; ^b Allegheny Intermediate Unit, 475 Waterfront Drive East, Homestead, PA 15120, USA

* Corresponding author.

E-mail address: lubetskyjmj@upmc.edu

Child Adolesc Psychiatric Clin N Am 23 (2014) 97–110

<http://dx.doi.org/10.1016/j.chc.2013.08.004>

childpsych.theclinics.com

1056-4993/14/\$ – see front matter © 2014 Elsevier Inc. All rights reserved.

coordination of care, similar to the “medical home” model, for the primary care physician. Many systems may be involved to provide services or funding resources and support to assist persons with ASD and/or Intellectual Disability (ID) and their families. More systems and services are available for children and adolescents with ASD/ID than for adults. Therefore, when adolescents leave the education system, they face greater challenges in obtaining services. There are also many hurdles during transitions from pediatric primary care and child behavioral health services to vocational services, adult medical care, and adult behavioral health services. Lubetsky and coworkers¹ have provided a comprehensive description of levels of care and services across the lifespan and a detailed list of references.

Coordination of multiple services is a challenge for families. For example, in the state of Pennsylvania, child systems include the following: Child Find, Alliance for Infants and Toddlers, early intervention services, local education systems, pediatrics, the Department of Developmental or Intellectual Disability/Autism, and the Department of Mental Health/Behavioral Health. At times, Child Protection Services/Child Welfare and Juvenile Detention may also be involved.

Adult systems in the state include the Department of Developmental or Intellectual Disability/Autism, the Department of Mental Health/Behavioral Health, and the Office of Vocational Rehabilitation. Other systems, such as junior colleges or universities, employers, and housing agencies, may also have important roles to play.

SYSTEMS OF CARE IN ASD ACROSS THE COUNTRY

States throughout the country are monitoring the increased prevalence of ASD and the growing numbers of adolescents transitioning to adulthood.² Most states are attempting to develop systems of care to meet the needs of individuals from early childhood through adulthood and their families.³ However, the ever-changing economic climate impacts funding streams for ASD/ID services under federal, state, and county line items, as well as Medicaid, Medicare, and private insurance.⁴

Many states strive to develop systems of care that include screening, diagnostic assessment, information and referrals, early intervention, behavioral support, applied behavioral analysis/functional behavior assessment, in-home care, skill training, parent training and education, respite care, case management, service coordination, supportive housing, supported employment, self-directed services—person-centered planning processes, service care planning, individualized budgeting, and quality assurance. In an effort to identify best treatment practices across the country, the National Standards Project reviewed intervention models and provided a best practices list of recommended services for children with ASD.⁵

The Center for System Change reviewed several state reports, and although recommendations cover many issues that impact individuals with ASD, there were several gaps identified.⁶ For example, Iowa identified the needs of siblings of individuals with ASD and recommended increased awareness and training. Cultural diversity is another area highlighted for better sensitivity and training. In addition, the report noted that although the need for mental health/behavioral health services is great, only 2 in 5 children with disabilities and poor psycho-social adjustment receive mental health services. Schools were identified as a critical site for behavioral health support, as well as the development of models for social skills training for students with ASD.

Much effort has focused on training pediatricians in identification of early warning signs of ASD and development of an autism pediatric practice “medical home” model.^{7,8} The “medical home” is designed to provide coordinated, accessible,

Download English Version:

<https://daneshyari.com/en/article/4150467>

Download Persian Version:

<https://daneshyari.com/article/4150467>

[Daneshyari.com](https://daneshyari.com)