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## Autism: Multidisciplinary Evaluation and Treatment. The LADDERS Model

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Autism Spectrum Disorder (ASD) is a developmental disorder characterized by impaired social interaction, delayed and disordered communication skills and isolated areas of interest. There is a growing appreciation that ASD is more complex than previously appreciate and in many cases, involves multiple organ systems beyond the brain. Those affected require intensive therapeutic services as well as skilled medical diagnosis and supervision. This paper describes a multidisciplinary clinical model in which the many services and interventions needed by ASD patients can be provided in a single site, reducing fragmentation of care and providing skilled diagnostic care and ongoing supervision.

**Keywords:** autism, behavior, medical co-morbidities, coordinated care.

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**For citation:** Bauman M.L. Autism: Multidisciplinary Evaluation and Treatment. The LADDERS Model. *Autizm i narusheniya razvitiya = Autism and Developmental Disorders*, 2020. Vol. 18, no. 3, pp. 22–27. DOI: <https://doi.org/10.17759/autdd.2020180303> (In Russ.).

## Аутизм. Мультидисциплинарная оценка и терапия. Модель LADDERS

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Расстройства аутистического спектра (РАС) — это нарушения развития, характеризующиеся трудностями в социальном взаимодействии, дефицитом и задержкой развития коммуникативных навыков, а также ограниченными интересами. В настоящее время растет понимание того, что РАС — более сложное состояние, чем считалось ранее; во многих случаях оно связано не только с мозгом, но и с другими системами органов. Люди с данными расстройствами нуждаются в интенсивной терапевтической помощи, а также в квалифицированной диагностике и наблюдении. В статье описана мультидисциплинарная клиническая модель, в рамках которой большое количество услуг и вмешательств, необходимых пациентам с РАС, может быть предоставлено в одном учреждении, что уменьшит разобщенность процессов оказания медицинских услуг и позволит обеспечить квалифицированную диагностику и постоянное наблюдение.

**Ключевые слова:** аутизм, поведение, сопутствующие заболевания, скоординированная помощь.

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**Для цитаты:** Бауман М.Л. Аутизм. Мультидисциплинарная оценка и терапия. Модель LADDERS // Аутизм и нарушения развития. 2020. Том 18. № 3. С. 22–27. DOI: <https://doi.org/10.17759/autdd.2020180303> (In Russ.).

Infantile autism is a behaviorally defined disorder first described by Leo Kanner in 1943 [8]. Since its original description, it has become apparent that the disorder is clinically, etiologically and biologically heterogeneous. Despite these differences, it is generally agreed that the core features of the disorder consist of a triad of clinical characteristics including impaired social interaction, delayed and disordered language and isolated areas of interest [5]. Additional features can include reduced eye contact, stereotypic and repetitive behaviors, sensory processing dysfunction and an insistence on sameness. Symptoms can range from mild to very severe. Until recently, it was believed that most individuals on the autism spectrum cognitively functioned in the mentally retarded range. However, current data suggests that fewer than half of those affected have a significant cognitive deficit [10].

Since its original description, the prevalence of the Autism Spectrum Disorders has been increasing, possibly in part due to improved recognition, expanded access to services and broadening of defining diagnostic features. According to the Centers for Disease Control and Prevention (CDC), autism is estimated to affect 1 in 59 children in the United States today [1; 2]. In many cases, ASD can be reliably diagnosed by the age of 2 years but some associated developmental delays are often evident earlier in life [9].

Since the 1980s, much of the research related to ASD has been devoted to the investigation and understanding of the underlying neurobiological mechanisms related to the clinical characteristic features of the disorder. Research approaches have included studies of gross and microscopic anatomy, neuroimaging, metabolic and genetic assessments, neurochemical and immunological mechanisms and studies of cellular connectivity. Although much progress has been, we still have much to learn.

Coincident with the expansion of basic science research has been the broadening of clinical investigations. As a result, there is now increasing evidence that ASD is a much more complex disorder than previously appreciated and may involve not only the brain but, in many cases, multiple organ systems. There is a growing body of literature documenting disorders such as gastrointestinal dysfunction, sleep disorders, metabolic abnormalities, urinary tract and hormonal involvement, allergies, obesity, osteoporosis, enlarged tonsils and adenoids, and PANDAS to name a few. Until the past 5-10 years, many of these disorders had been

overlooked, possibly because many ASD patients can be difficult to examine. Many are non-verbal and cannot express their pain and discomfort or accurately localize their discomfort. Still others may present with symptoms that are not easily recognized as signals for underlying medical conditions by the average practitioner such as episodic disruptive behaviors that may signal discomfort [3].

In addition to their multiple medical disorders, children, adolescents and adults on the autism spectrum present with developmental challenges that require specialized and intensive interventions including speech and language services, occupational therapy, physical therapy, applied behavior analysis (ABA), social skills intervention, access to assisted technology, special education approaches and transitional planning into adulthood including secondary education opportunities and vocational exploration. From the perspective of the average family, locating and providing needed interventions for their autistic child or young adult can be confusing and often extremely stressful.

### The Birth of the LADDERS Program

In the 1960s, federally supported programs were established in the United States during the Kennedy administration designated as University Affiliated Programs (UAPs) [7; 12]. Each academically associated UAP provided a multidisciplinary team designed to evaluate individuals with developmental disabilities, including those residing in mental institutions, with the goal of moving these clients from these settings out into the community. These programs involved a broad range of professional disciplines including Neurology, Psychiatry, Nursing, Audiology, Speech Pathology, Psychology, Occupational Therapy, Physical Therapy, Social Work, Special Education and a Vocational Specialist. Team members each evaluated the same patient over a two-week period after which results were shared within the team, discussed with the client's family and plans made for community placement. Not only was this an exceptional evaluation opportunity for the patient and his/her family, but the program provided a valuable teaching model for team members, each of whom was able to learn from their colleagues. It was against the background of the UAP model that the concept of LADDERS (Learning And Developmental Evaluation and Rehabilitation Services) was created.

LADDERS began in the late 1980s, initially centered in a rehabilitation hospital in Cambridge, Massachusetts. In contrast to the UAP model, the LADDERS approach included not only the evaluation of the patient, but also program planning, direct therapy on site, and ongoing follow-up. Initially, the program was focused on the assessment and provision of services for students with learning differences (Learning Disabilities). However, the client population began to change during the early 1990s as the result of the then growing body of research being conducted in autism and with the increased awareness of this disorder. Thus, from that point forward, the focus of the program rapidly changed to a center dedicated to the diagnosis and treatment of children, adolescents and adults with autism. During the mid-2000s, the program came under the administration of one of the major teaching hospitals in eastern Massachusetts, a relationship that helped to foster the education of doctors in training as well as undergraduate and graduate students, and provided a rich environment for interdisciplinary clinical research.

### **The Expansion of the LADDERS Program**

By 2003, the majority of LADDERS patients were being referred from sites throughout all of the New England states as well as New York and New Jersey. 90% of these patients carried a diagnosis of ASD, with the remaining patients presenting with other types of learning and developmental disabilities. Patients were typically referred by primary care physicians, educators, therapists, family members and Early Intervention Agencies. Initially, the focus of a first-time referral was to the medical staff and was devoted to making or confirming a specific diagnosis. Later, however, an equal number of requested assessments were directed toward the therapeutic staff with requests to define the patient's therapeutic and educational needs and to help families locate needed quality services near their respective homes. The provision of direct on-site therapies, including speech and language intervention, Occupational Therapy and Physical Therapy were also added. Ongoing monitoring of the patient's progress then became an integral part of the program in order to insure that the services provided were effectively meeting each patient's needs and allowing each client to make meaningful progress.

### **Program Structure**

A patient referred to LADDERS was initially processed by an Intake Coordinator who conducted a telephone interview, usually with the parent, in order to identify the reason for the referral in order to be able to direct the patient to the appropriate provider. An initial appointment was scheduled and an Intake Packet was mailed to the family requesting past medical and developmental history as well as copies of previous medical and educational records. Typically, the patient would be first seen by one of the clinic physicians who, based on the information provided and the physical and neurological evaluation, would determine what laboratory studies and medical and therapy assessments would be needed to define the patient's diagnosis and therapeutic needs. Upon completion of these evaluations, the physician would meet with the patient's parents/caregiver to review the findings and recommendations, and provide appropriate resources for therapies and interventions. Following the initial assessments, ongoing periodic monitoring was provided, with follow-up visits typically scheduled every 3–6 months.

### **The LADDERS Team**

Although LADDERS began its life under the administration of a rehabilitation hospital, it later became overseen by a joint agreement between an acute care academic teaching hospital and a rehabilitation facility. Specialty areas supported by the acute care academic hospital included Developmental Pediatrics, Adult and Child Neurology, Internal Medicine, Adult and Child Psychiatry, Neuropsychology, Social Work, Family Resource Coordinator/Patient Navigator, Gastroenterology and Education Specialist.

Disciplines supported by the Rehabilitation Hospital included Occupational Therapy, Physical Therapy, Speech and Language Pathology, Nutrition/Feeding Specialist and Assisted Technology/Communication Device Specialist.

A clinical program such as LADDERS cannot reasonably support every potential discipline that any one patient might need on site. It is therefore important that quality community based therapeutic and medical resources must be identified with whom this program could collaborate. Further, such resources cannot be only identified locally, but since many patients have been referred from throughout

the northeast region of the United States and beyond, resources need to be sought near where any specific patient resides. Seeking and identifying skilled resources becomes the job of the Family Resource Coordinator/Patient Navigator in collaboration with other clinic providers [6]. The identification of skilled medical and therapeutic care and educational programs on behalf of the patient is as important as making the initial diagnosis. Without quality intervention and treatment programs, the chances that the patient can and will make the progress of he/she is capable remains uncertain.

In addition to identifying appropriate therapeutic sites near a patient's home, needed community based medical resources are many. Individuals on the autism spectrum can experience many of the health conditions impacting their typically developing peers. However, it is essential to identify resources experienced in working with the autistic population because these individuals can present with symptoms not easily recognized by the average medical provider or specialist. Some of these resources include Medical Genetics, Sleep Disorders, Allergy, Urology/Nephrology, Endocrinology, Otolaryngology, Developmental Optometry, Ophthalmology, Audiology, Dental care, Orthopedics, Behavioral Psychology, Infectious Disease, Educational Advocacy, Educational Law and Social Skills agencies.

### **The LADDERS Program now**

In 2003, the concept of the multidisciplinary program/medical home for individuals on the autism spectrum was presented at a conference in Seattle, Washington. Following this presentation and with the aide of philanthropic resources, it was elected to create a collaboration of similar programs throughout the United States. As a result, the Autism Treatment Network (ATN) was established under the guidance of the Northwest Autism Foundation in Portland, Oregon with the goal of creating a network of academically based multidisciplinary centers that would develop mutually agreed upon protocols focused on the documentation and assessment of prevalence, presenting clinical features and treatment of comorbid medical conditions across the autism spectrum. Later, in 2008, the ATN came to be incorporated into the work of Autism Speaks, currently the largest autism advocacy organization in the United States. Although the ATN has undergone changes in collaborators, personnel and fund-

ing over time, the program continues to thrive under the auspices of Autism Speaks and now includes 12 sites, two in Canada with the remaining 10 programs located throughout the United States [4].

Despite its changes and growth over time, the goals of the ATN have remained consistent and include, 1) the establishment of scientifically sound and meaningful standards of healthcare for those on the autism spectrum, 2) the establishment of evidence based data with regard to medically related conditions in autism, 3) the provision of a forum for collaborative hypothesis-driven clinical research across the network and 4) the provision high quality care for those on the autism spectrum by identifying and implementing best practices [11]. Over the past several years, the ATN, with the support of Autism Speaks, has created and maintained a clinical patient registry, which now includes close to 7000 children with autism. This registry has gathered follow-up data allowing a review of changes over time in some of the characteristics and health care needs of ASD children. This data has been made available to both internal and external investigators, resulting in doctoral dissertations and peer-reviewed publications [11].

### **Medical Comorbidities**

With advances in clinical care, there has come the appreciation that many children, adolescents and adults on the autism spectrum experience medically significant disorders that may negatively impact their developmental progress and behavior, but which frequently go undetected. Many of these conditions are treatable, and when identified and addressed, can improve developmental trajectory and quality of life for both the patient and his/her family/caregivers. Some of the more common medical conditions include seizures, sleep disorders, gastrointestinal dysfunction, obesity, metabolic conditions, hormonal imbalances, and psychiatric disorders including anxiety, attention deficit disorders, obsessive compulsive disorders and depression. Additional conditions that are now receiving increased attention include osteoporosis, otitis media, bladder and renal disorders, hypertension, diabetes, dental pain and immune disorders. In many cases, more commonly in those patients who are non-verbal, these disorders many present in an atypical manner, often with the patient demonstrating disruptive behaviors including aggression,

self-injury and screaming. There is a growing recognition that many of these behaviors may reflect pain and discomfort in a patient who cannot verbally express his/her distress or accurately localize the cause of their discomfort. Thus, there is an increasing consensus that any patient presenting with unexplained disruptive behaviors merits a detailed medical assessment before assuming that these behaviors are “just part of their autism”/

### **Multidisciplinary Programs — the benefits and challenges**

The creation and development of multidisciplinary centers focused on the evaluation, treatment and advocacy for individuals on the autism spectrum provides a numbers of advantages and resources, both for families as well as providers. Although ASD is becoming an increasingly common disorder, there are still situations in which the diagnosis of autism is missed or overlooked. This most often occurs in the very young child, in individuals with “high functioning autism” and in females, many of whom have been labeled with a variety of psychiatric conditions. The availability of high quality, skilled autism centers can provide a site where families and caregivers can confidently seek and obtain accurate assessments and scientifically sound recommendations for interventions and services. Further, once a diagnosis and recommendations are made, a multidisciplinary site can provide additional evaluations and needed therapeutic interventions in the same location, thus preventing fragmented care. Offering ongoing multiple services for families in the same site reduces stress on parents/caregivers, while increasing opportunities for therapists and medical staff to communicate with each other and to carry over strategies and interventions across disciplines, thereby enhancing treatment approaches and effectiveness.

Ongoing educational opportunities for staff is a critically important feature of a multidisciplinary program. Many physicians do not receive an in-depth exposure to speech pathology or occupational and physical therapy as it relates to the evaluation and treatment of individuals with special needs as part of their training. The availability of other disciplines evaluating the same patient teaches providers on the team to appreciate and learn from the insights of others, a very valuable lesson, and often allows them to see what they may have missed as

part of their own assessments. Complementing the education of the team staff is the importance of providing meaningful training for medical students, interns and residents, as well as graduate and undergraduate students. Providing such training in such an academic multidisciplinary and cross-disciplinary site is an unprecedented opportunity, especially given the increasing numbers of individuals identified with ASD. Regardless of what medical or therapeutic field a student eventually selects for his future career path, almost all will become involved with patients on the autism spectrum at some point and they will need to be adequately prepared when that time arises. Experience in a high quality multidisciplinary program should be able to provide a strong background for their future.

In addition to the important clinical opportunities offered by a multidisciplinary approach is the provision of an environment that encourages interdisciplinary research. The ATN has provided a leadership role across its multiple sites focused on a number of important comorbid medical conditions including constipation, sleep disorders as well as dental health and obesity. The opportunity to create and utilize a common registry and database that includes a large number of well-documented patients provides an invaluable resource for present and future research. There is no doubt that a collective and well-designed database will play an important role in pursuing future research including studies that will lead to a better understanding of the underlying neurobiology of the disorder as well as defining potential subgroups, identifying differences between males and females on the spectrum and documenting the life long trajectory of this disorder.

While there are many strong advantages to the availability of multidisciplinary autism centers, there are also challenges. One of the major areas of concern is the financial support needed to sustain these programs. While insurance can cover the cost of some the medical and therapeutic expenses, there continues to be significant gaps in financial resources. The ATN has been supported by Autism Speaks as well as funding from the Health Resources and Services Administration (HRSA) to become the Autism Intervention Research Network on Physical Health (AIR-P). This funding has been critically important for the support of ongoing research efforts and much of the resulting published data. However, despite federal and healthcare insurance support, there is still a need for philanthropic efforts to cover administrative costs and the salary of some

staff who, while being critically essential members of the team, are non-revenue producers.

## Conclusion

Autism spectrum disorders are complex, behaviorally defined developmental disorders characterized by impairment of social interactions, delayed and disordered language, repetitive behaviors and restricted areas of interest. Over the past 10 years, there has been a growing awareness that these disorders are often associated with significant medical comorbidities, many of which have been overlooked. When identified and treated, patients show improvement in their development trajectory and quality of life. The availability of multi-

disciplinary centers providing skilled evaluation and treatment resources can have a critically important impact on the developmental outcomes for those on the autism spectrum. These centers can offer scientifically based health care and therapeutic interventions, provide interdisciplinary treatment approaches, reduce fragmentation of care, provide educational opportunities for staff and students and offer important avenues for clinical research. The LADDERS program provides an example of one such clinical approach but other models may be equally effective depending on the needs and environment of the community in which a specific site may be located. Integrated and collaborative care is an important approach to this complex disorder and can improve short and long term outcomes. ■

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Получена 05.06.2020

Received 05.06.2020

Принята в печать 11.08.2020

Accepted 11.08.2020