

FORESIGHT-SESSION: “HEALTH CARE SERVICE FOR CHILDREN WITH AUTISTIC SPECTRUM DISORDERS”

Natalia Ustinova, R.N. Terletskaia & E.V. Antonova

National Medical Research Center for Children's Health, Moscow, Russia

Background: Autism Spectrum Disorders (ASD) are a global problem due to the high prevalence and significant health and social consequences. All over the world, people with ASD continue to face major challenges including social stigmatization, isolation and discrimination, and that children and families in need often have poor access to appropriate medical support. It's time to state about needed of reorganization of health care services for children with ASD.

Aim: Strategic planning of the development of appropriate medical support for children with ASD.

Subjects and methods: A 4-hours foresight-session “Health care service for children with autistic spectrum disorders” was held with the support of the autonomous non-profit organization “Center for Autism Problems” and non-governmental organization “Contact”. The session was moderated by a business coach of SAP - a global company and a leader in the Russian business solutions market. During the session, 8 working groups were created, each of which included representatives of parents (parents of children with ASD) and doctors (psychiatrists, neurologists, pediatricians, gastroenterologists, public health specialists) - from 9 to 11 people in each group. The main problems of the health care service for children with ASD were discussed and solutions were introduced by each group. Finally a consolidated strategy has been developed for the reorganization of health care service for children with ASD.

Results. Key problems of health care for children with ASD were identified and the solutions were outlined.

1. Lack of an early identification system for autism spectrum disorders. There was an opinion which was supported by the parents and the medical societies, that pediatricians are not familiar with the signs of autism. There were cases when parents concerned about delaying and deviations in the child's mental development, but pediatrician reassured that “don't worry,” or “boys begin to talk later.” Parents had to insist on a proper medical examination of their child.

2. Stigma. Despite the positive changes in the mental health care in recent years, most parents rate it as unsatisfactory. Continuing separation of psychiatric and other types of medical care is contrary to the principles proclaimed by WHO. The main troubling for parents with newly diagnosed “ASD” were “registration system”. For those who had experience with psychiatric services, dissatisfaction caused unjustified hospitalizations, especially the common practice of hospitalizing a child in a psychiatric hospital without a parent. Additionally parents were not satisfied in psychiatric care due to unjustified prescription of antipsychotics, often in high doses. At the same time, interventions that are proven and recognized throughout the world (for example, ABA-therapy) are not offered by psychiatrist. Some parents reported that they were forced to “fight for the diagnosis of autism.” Psychiatrists with whom they had to deal, prefer the diagnosis of “mental retardation”, ignoring the deficit in social communication and specific behavioral pattern. Misdiagnosis leads to the fact that children do not receive adequate educational services, since rehabilitation focuses solely on the problem of quantitative reduction in intelligence. In addition, parents convinced by a doctor in the absence of autism do not show the necessary efforts to rehabilitate a child with ASD. However, it is established that the family educated in the problem of autism is the key to the effectiveness of therapeutic interventions.

3. Insufficient health care service for children with ASD. There were indicated numerous problems associated with ASD health care. For example, problems can be as late diagnosis of some rare diseases, as well as the inability to treat caries due to insufficient staff training. Parents complain that they hardly manage to attract the attention of specialists to the somatic problems of their children, for example, to gastrointestinal issues (selectivity in food, constipation, etc.). However, it is known that the prevalence of gastrointestinal disorders in children with ASD is 4 times higher than that of their peers with normal development. At the same time, proper treatment of these disorders reduces the intensity and frequency of behavioral disorders. Children with ASD often cannot receive proper health care both in psychiatric or pediatric care services. Psychiatric services are not focused on a comprehensive medical examination. Some symptoms, which may indicate the need for in-depth examination (distorted appetite, physical discomfort, sleep disorders), are traditionally considered only within the framework of a mental disorder. In pediatric services problems are associated with complexity of medical comorbidities in autism, atypical clinical features. Additionally, the staff is not trained enough to conduct diagnostic and therapeutic interventions for children with ASD.

Conclusion: Strategic planning for the improvement of health care for children with ASD should include the following measures:

- Development of the system of early identification of ASD. Using of special questionnaires in primary health care to identify a risk group and risk factors. Special training for district pediatricians in the field of developmental disorders and ASD, focus of health care for this children.
- The development of personalized and multiprofessional approach and taking into account all the clinical signs.
- Comprehensive medical examination of children with developmental disorders (including ASD) in pediatric (non-psychiatric) medical services with the involvement of a multidisciplinary team of specialists.

The first step is the approval of the Ministry of Health of Russian Federation to conduct a project “The Model of multidisciplinary health care for children with ASD in paediatric setting” by National Medical Research Center for Children's Health (laboratory of social paediatrics).

* * * * *

A MULTIDISCIPLINARY APPROACH TO THE MANAGEMENT OF PATIENTS WITH AUTISM SPECTRUM DISORDERS

Natalia Ustinova, R.N. Terletsкая, L.M. Kuzenkova, T.E. Borovik, T.V. Bushueva, E.V. Antonova & I.V. Vinyarskaya

National Medical Research Center for Children's Health, Moscow, Russia

Background: According to the WHO, 1 child in 160 in the world has an autism spectrum disorder (ASD). Moreover, it is indicated that in some well-controlled studies, significantly larger numbers are reported.

In recent years, ASD studies have not being seen solely within the narrow framework of child psychiatry. There are number of works which indicate to concomitant (non-mental) disorders in patients with ASD, that have a significant impact on the behavior of patients (disorders of the digestive system, allergies, pain, physical discomfort etc.). The need for enhanced therapeutic approaches in the healthcare delivery to children with autism is becoming increasingly apparent. Despite significant efforts to improve the delivery of health-care services for children with ASD, there is still no proper continuity in work between psychiatric and pediatric institutions in provision of medical aid. As a consequence of this is an unacceptable gap in the health-care services delivery, creating potential problems of socialization and habilitation of such children.

Purpose: Justify approaches to the development of a model of multidisciplinary support for children with ASD.

Subjects and methods: The electronic databases of scientific information Medline, Web of Science, Scopus, PubMed, Cochrane Database of Systematic Reviews were used to search for articles published in peer-reviewed scientific journals devoted to issues of concomitant non-mental disorders in children with ASD. The existing domestic clinical guidelines and standards of specialized medical care for children with common disorders of psychological development (autism spectrum) were analyzed. The profile experts (pediatricians, neurologists, genetics, gastroenterologists, nutritionists, allergists, immunologists and psychiatrists) were involved to the evaluation of the received information. According to their assessments the approaches to the development of multidisciplinary support model for children with ASD have been developed.

Results: From the end of the twentieth century to nowadays, the growing interest in the problem of concomitant diseases connected with ASD is reflected in a number of scientific publications devoted to this topic. The direct connection of disorders (changes) of behavior in children with ASD has been demonstrated in studies that had been focused on such conditions as gastrointestinal disorders, allergy, premenstrual syndrome, otitis etc. There were indicated that behavioral disturbances often occur due to a pain and discomfort that accompany a somatic illness.

A high prevalence of epilepsy in patients with autism is well known. According to various studies these figures are from 20% to 50%. The high probability of such combination is taken into account in Russian clinical guidelines and standards of specialized medical care for children with common disorders of psychological development (autism spectrum).