SPECIAL ARTICLE: Korean Practice Guideline for Autism Spectrum Disorder
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History of the Task Force for the Korean Clinical Guidelines of the Developmental Disorders

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Under the Ministry of Health and Welfare of the Republic of Korea, the National Autism and Developmental Disorder Centers for people with developmental disabilities are gradually expanding. The headquarters of the National Autism and Developmental Disorder Center provides support for education, training, and research, and several centers have been effectively operating since 2020. This study aimed to provide practical recommendations and guidelines for specialists such as clinical psychologists, child psychiatrists, allied professionals, community workers, and related administrators. It was developed as a guideline to promote early diagnosis, provide important information on integrated treatment, and assist people with developmental disabilities in Korea to make the best decisions for their quality of life.

Keywords: Autism spectrum disorders; Developmental disabilities; Intellectual disability; Practice guideline.

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BACKGROUND OF DEVELOPING THE GUIDELINE FOR DEVELOPMENTAL DISABILITIES

The diagnosis name and criteria for the pervasive developmental disorder were changed to autism spectrum disorders (ASD) when the Korean Academy of Child and Adolescent Psychiatry (KACAP) released "The Korean Practice Parameter for the Treatment of Pervasive Developmental Disorders" in 2007 [1-5]. However, as new information is obtained through various research studies and literature reviews, there is a need to develop clinical guidelines based on this new information. While parameters from 2007 gave accepted recommendations based on the latest findings, treatment recommendations scored low on the quality evaluation as a clinical guideline.

The results of the Korean Appraisal of Guidelines, Research, and Evaluation (K-AGREE II) [6,7], conducted by the Korean Medical Association in 2013, targeted 47 Korean clinical guidelines published between 2007 and 2009 (evaluation results of individual guidelines were not disclosed). The average score of the 47 Korean clinical guidelines was low, ranging from 50.9% to 5.2% in all areas [8]. Non-disclosure of practicality in the medical field and conflicting interests of members who participated in guideline development were specifically identified as problems. Feedback on the 2007 recommendations included the requirement for an easy-to-understand guidebook for people with ASD, their families, and caregivers, which became the basis for promoting the development of new clinical guidelines.

The primary purpose of developing the Korean version of the Developmental Disorder Clinical Guideline was to build an evidence-based diagnostic process for treating developmental disorders, such as autism, and to manage and standardize the treatment quality in clinics and hospitals.

PROCESS OF THE TASK FORCE FOR DEVELOPING THE GUIDELINE

From March to July 2021, the headquarters of the National Autism and Developmental Disorder Center Clinical Subcommittee (chaired by Prof. Joung-Sook Ahn) held five meetings and corresponded with working-level members, including directors of eight regional National Autism and Developmental Disorder Centers located in Seoul, Incheon, Busan, Gyeonggi-do, Gangwon-do, Chung-cheong bukdo, Jeolla bukdo, and Gyeongsangnam-do. The guiding principles, procedures,

and authors of the guidelines were discussed at these meetings. After literature analysis, the establishment of clinical guidelines, and internal reviews, a draft was prepared from August to October 2021, which passed through the first and second revisions. Professionals from each field assembled a review committee in November 2021 to review draft clinical guidelines. The Korean Developmental Disorders Clinical Guidelines were completed in March 2022. The "K-AGREE II: Korean Appraisal of Guidelines for Research and Evaluation II" [6] was referred to while writing and reviewing the new guidelines, and "The GuideLine Implementability Appraisal (GLIA)" [9] was used for preliminary assessments of recommendations in the "Korean Clinical Guidelines 2022" for three months. This applicability evaluation is available online at http://nadd-snuh.org/.

The following organizations were involved in this process:

1) Working Committee: This committee consisted of 12 people, including the directors of eight regional National Autism and Developmental Disorder Centers and staff from the Headquarters of the National Autism and Developmental Disorder Centers. They discussed and made decisions on all issues related to the development of the guidelines.

2) Authors: Subjects of developmental disorder diagnostic evaluation and intervention were divided into six areas, with two to three authors assigned to each area. They included four clinical psychologists in charge of non-medication intervention approaches, directors of eight regional National Autism and Developmental Disorder Centers, and three developmental disability specialists who contributed to creating the Korean intervention recommendation in 2007.

3) Review Committee: Participants included 17 people who received draft recommendations from the Working Committee, academic organizations, and civic groups. These 17 included 10 medical professionals, five non-medical specialists working for people with developmental disabilities, and one representative from relevant organizations and civic groups. After examining the guidelines, committee members were asked to evaluate them using the K-AGREE II and make recommendations.

PRINCIPLES FOR THE TASK FORCE WHEN DEVELOPING THE GUIDELINE

Developing Korean clinical guidelines is challenging because few evidence-based studies, such as cohort studies and randomized controlled trials have examined people with developmental disabilities. Adopting and developing current internationally recognized clinical guidelines has been suggested as an expedient way to resolve this dilemma [10]. However, modifying international guidelines for various social and medical situations in Korea is challenging [11]. Therefore, the Working Committee decided to develop a new guideline based on the existing Korean clinical guidelines, such as the "Korean Treatment Recommendation for Pervasive Developmental Disorder" (2007) and "Problem Behavior Intervention Guidelines for Child and Adolescent with Developmental Disorder" (2018) [12], as well as five international clinical guidelines and 10 research articles that were published in the past 10 years. Internationally recognized clinical guidelines include the American Academy of Child and Adolescent Psychiatry (AACAP) Practice Parameters (2014) [13], New York State Guidelines (2017) [14] from the United States, National Institute for Health and Care Excellence (NICE) Guideline (2011–2013) [15-17], Scottish Clinical Guidelines (2016) [18] from the United Kingdom, and ESCAP Clinical Guidance (2020) from the European Union [19]. Search phrases such as "developmental disorder," "autism," or "autism spectrum disorder" were used in databases such as PubMed, Embase, Cochrane Library, and Scopus. Recommendations and best practices based on clinical experience described in this guideline comply with the Level of Evidence of the Scottish Clinical Guidelines [18] and the Clinical Standard of the American Academy of Child and Adolescent Psychiatry [13]. These guidelines were adopted from the main text of each guideline, considering their applicability in Korea.

The Working Committee established the following principles to ensure that the development of the new guidelines was effective, practical in the field, and true to the evidence.

1) Clinical guidelines are defined as a convenient document that "develops and evaluates the communication strategies to support informed decisions and practice based on evidence" [20] and the consumer makes the final decision in the clinical practice stage. Consequently, developing "ASD-friendly" guidelines will optimize its use.

2) ASD emerges during the first few years of infancy and persists throughout life, resulting in a wide range of symptoms. In this context, it is natural that a diagnostic evaluation and intervention plan for people with ASD should be established considering the developmental level, age, sex, comorbidities, and available resources. Unlike previous guidelines that focused on infancy and childhood, the scope of these guidelines includes the entire life cycle from infancy to old age, sex differences, and social integration issues.

3) To help readers understand the new guidelines, medical terminology and jargon were reduced as much as possible, the proportion of non-medication interventions was increased, and some treatments not recommended to advise appropriate choices for people with ASD and their families were clarified.

GLOSSARY

According to the Korean Welfare of Disabled Persons Act, developmental disabilities include intellectual disabilities and ASD [21]. While this is crucial for academic research, clinical evaluation and intervention place less emphasis on clearly separating ASD from intellectual disability. This is because early interventions focused on improving communication should begin immediately when concerns are recognized rather than waiting for a child with developmental delay to be diagnosed with ASD or intellectual disability [22]. Additionally, these two types of developmental disabilities are genetically and clinically common in many aspects [23,24]. People with moderate or severe intellectual disabilities may exhibit secondary features [22]. Consequently, rather than providing an accurate diagnostic classification, these clinical guidelines for developmental disabilities emphasize support for interventions to meet the individualized needs of persons with developmental disabilities. Notably, they were developed with a focus on ASD in combination with intellectual disabilities.

Unless otherwise stated, the term "person with developmental disability" refers to an ASD-diagnosed individual, and "family" refers to the primary caregiver, regardless of the parent-child relationship. The term "developmental disorder specialists" refers to pediatric psychiatrists, pediatric rehabilitation medicine doctors, and pediatric neurology specialists who are likely to encounter individuals with ASD for the first time. The term "clinician" refers to all specialists involved in the diagnostic evaluation and intervention of ASD.

LIMITATIONS

However, these clinical guidelines do not aim to define a single standard of care for patients with ASD. The best clinical data for each individual with ASD were used to set the standards of care, and modified based on the evolution of medical knowledge and treatment techniques. Furthermore, the present guidelines do not guarantee successful results in all cases. Therefore, these guidelines should not include or exclude all appropriate treatment methods. Therefore, after engaging in a thorough conversation with an individual with ASD and their family, considering the circumstances they are facing, as well as the diagnostic evaluation, treatment options, and available resources, clinicians should make the final decision regarding diagnostic evaluation and intervention.

FOLLOW-UPS AND UPDATES

These clinical guidelines will be published in 2023, followed by a 5-year review and update. The review history and updates during the interim period will be documented in the review report, which will be available on the official website of the Headquarters of the National Autism and Developmental Disorder Center.

Availability of Data and Material

Data sharing is not applicable to this article as no datasets were generated or analyzed during the study.

Conflicts of Interest

The authors have no potential conflicts of interest to disclose.

Author Contributions

Project administration: Bung-Nyun Kim. Writing—original draft: Bung-Nyun Kim. Writing—review & editing: Joung-Sook Ahn.

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