Comparison of Services for Autism Spectrum Disorder in Massachusetts with Those in Seoul

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ABSTRACT

Background: This article intended to identify and describe areas in need of services and interventions for individuals with autism spectrum disorder (ASD) and their families in Seoul, Korea.

Methods: A descriptive comparison was made between available services and interventions in Seoul, Korea and Massachusetts, USA. Relevant information was obtained through sending phone/email inquiries to the governments and organizations, visiting their official websites, and searching for published articles or reports.

Results: In a few areas such as level of education, economy, and general quality of healthcare, Seoul was found to be similar to Massachusetts. However, in terms of services and interventions for individuals with ASD and their families, especially early identification and intervention, special education, care coordination, school-based programs, and transition to adulthood, Massachusetts was shown to have far more availability.

Conclusion: The limited availability of services and interventions for individuals with ASD and their families in Seoul in comparison to Massachusetts, underlines target areas for further investment and development.

Keywords: Autism Spectrum Disorder; Intervention; Massachusetts; Seoul; Services

INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterized by deficits in social interaction and communication and repetitive and restricted patterns of behaviors and interests.1 Although the prevalence of ASD in the USA is as high as 1 in 58 children as evidenced by the latest Centers for Disease Control (CDC) estimates, the prevalence rates vary from 13.1 to 29.3 per 1,000 children among different racial/ethnic groups and communities throughout the US.2 There are more significant differences in the prevalence of ASD internationally, ranging from 0.3 per 1,000 children in Poland to 26.3 per 10,000 children in Korea.3-5
Currently, there is no consistently effective pharmacologic treatment for the core symptoms of ASD. Early identification and early intensive behavioral interventions are believed to improve outcomes for the disorder. In an Autism Treatment Network (ATN) study, 79% of toddlers and preschoolers with ASD had received at least one treatment service, and 28% had received behavioral services. However, health service utilization also varies according to race or ethnicity for children with ASD. Moreover, available services for ASD and the health service utilization rates are different across countries. In a Korean population-based study, two-thirds of school-age children with ASD in the mainstream school system were undiagnosed and untreated, and it was reported that no specific intervention program was provided in mainstream schools for children with ASD in mainland China. However, different utilization patterns of healthcare or community-based services across different countries have yet to be studied.

Seoul, the capital of Korea, is often praised as one of the leading cities in the world in terms of technology, safety, and education. Efficient and affordable access to high quality medical care is another aspect that differentiates Seoul from many other cities in the world. Despite its excellent medical system, however, only a little progress has been made in Seoul toward treatment or services for ASD. Most psychosocial treatment or services are not covered by Korea’s National Insurance System, and school-based interventions and support systems are sparse in Korea. The Commonwealth of Massachusetts, a state located on the Northeastern coast of the USA is comparable to Seoul in its emphasis on education, economy, and advanced level of general medical care. In contrast, the level of available services provided by the government, school systems, and healthcare institutions, for patients and families with ASD is significantly greater in Massachusetts. Moreover, based on an online survey by Autism Speaks, the greater Boston area (Boston is the capital of Massachusetts) was rated as one of the top places to live for individuals with ASD.

Here, the authors aim to demonstrate the need for more services and supports for individuals with ASD and their family members in Seoul, by comparing those that exist in Seoul to those currently available in Massachusetts.

**METHODS**

The authors utilized various sources of information to generate a list of the different services and supports currently available for the care of individuals with ASD and their family members in Seoul, Korea and Massachusetts, USA.

General information, including census and demographics, was obtained from official government websites or documents, such as the Seoul Open Data Plaza, Seoul Education Statistics, Seoul Special Education Statistics, and U.S. Census Bureau. For the availability of the therapeutic programs and services, previously published articles or reports on services for ASD, and internet search engines, such as Google and Naver, were used with relevant search terms including the names of specific services (e.g., ABA). Official websites for organizations, such Autism Speaks and the Autism Society of Korea, were searched for relevant information. Email or phone inquiries were sent to relevant associations/organizations, including the Korean Academy of Child and Adolescent Psychiatry, Korean Child Neurology Society, Korean Clinical Psychology Association, and American Psychiatric Association, seeking information that was not available on the internet. The authors’ clinical
experience was also utilized to ensure that the information sought through various sources was consistent with their day-to-day treatment of patients with ASD and their family members.

**Ethics statement**
The current study is a descriptive comparison and therefore did not require statistical analysis. Also, Institutional Review Board permission was not required as the current study did not involve collection of data from any human subjects.

## RESULTS

Table 1 shows the comparison of general statistics in Seoul and Massachusetts. Seoul, the largest city and capital of Korea (233.69 mi²), is geographically one thirtieth of the size of Massachusetts (7,800.06 mi²). Despite this significant difference in size, Seoul (9.86 million) is about 1.5-fold as populous as Massachusetts (6.86 million). Thus the population density is far greater in Seoul than in Massachusetts (44,032.69/mi² vs. 879.48/mi²). Massachusetts has a higher median annual income than Seoul (70,965 USD vs. 51,050 USD). However, based on a 2018 report by the Economist Intelligence Unit, Seoul is ranked the sixth most costly city in the world with an index score of 106, as compared to that of New York at 100; no city in the U.S. including Boston is listed in the top ten. Seoul and Massachusetts have comparable levels of education (e.g., bachelor’s degree or higher in more than 40% of the population in both places).

In Seoul, 5,043 patients are registered with the National Registry for ASD. However, when we apply the 1.89% prevalence rate for ASD in the general population from Kim et al.’s study, four patients are estimated to be registered.

### Table 1. Comparison of general statistics in Seoul and the Commonwealth of Massachusetts

| Category                        | Seoul                              | Massachusetts                      |
|---------------------------------|------------------------------------|------------------------------------|
| **General**                     |                                    |                                    |
| Population                      | 9.86 million (2017)\(^{15}\)       | 6.86 million (2017)\(^{18}\)       |
| Area                            | 605.25 km² (233.69 mi²)\(^{15}\)    | 7,800.06 mi²\(^{18}\)             |
| Economy (median family annual income) | 51,050 USD (1 USD = 1,050 KRW)\(^{15}\) | 70,965 USD (2012–2016)\(^{18}\) |
| Education                       | Bachelor’s degree or higher 40.7%  | Bachelor’s degree or higher and age ≥ 25 years (2012–2016) = 41.2%\(^{18}\) |
|                                 | High school graduate or higher 85.4%\(^{15}\) | High school graduate or higher and age ≥ 25 years (2012–2016) = 90.7%\(^{18}\) |
| **Patients**                    |                                    |                                    |
| No. of patients with ASD        | Registered at 5,043\(^{15}\)       | Registered: unavailable            |
| Approved special education schools | Estimated at 28,544 (in 2017, under age 18 years) | Estimated at 20,383 (in 2015, under age 18 years)\(^{24}\) |
| Mainstream schools with         | A total of 29, of which 6 are schools for the blind and deaf. Eighteen for intellectual disability and ASD.\(^{15}\) | A total of 167, of which 7 are schools for the blind, 8 schools for the deaf. Thirty-eight self-identified as specifically serving students with ASD. Forty-nine residential and 25 collaborative programs.\(^{23}\) |
| therapeutic capacity            | Kindergarten 67 of 906\(^{17}\)    | All schools have therapeutic capability |
|                                 | Elementary school 264 of 602\(^{27}\) | Elementary public-school 1,113\(^{23}\) |
|                                 | Middle school 192 of 388\(^{17}\)  | Middle/junior high school 330\(^{23}\) |
|                                 | High School 204 of 326\(^{17}\)    | High School 404\(^{23}\)           |
| **Clinicians**                  |                                    |                                    |
| Physicians                      | Psychiatry 731\(^{18}\) (CAP 191\(^{18}\)) | Psychiatry 2,030\(^{37}\) (CAP 475\(^{38}\)) |
|                                 | Pediatrics 1,236\(^{15}\) (Child Neurology 50\(^{26}\)) | Pediatrics 2,081 (51 Developmental-Behavioral Pediatricians,\(^{29}\) Child Neurology 171\(^{39}\)) |
| Psychologists (PhD + PsyD)      | 700\(^{31}\)                      | 6,168\(^{32}\)                    |
|                                 | - 68 BCBA/BCABAs/BCBA-Ds           | - 2,064 BCBA/BCABAs/BCBA-Ds        |
|                                 | - 12 RBTs                          | - 796 RBTs                        |

ASD = autism spectrum disorder, CAP = child and adolescent psychiatrists, PhD = doctor of philosophy, PsyD = doctor of psychology, BCBA = board certified behavior analyst, BCABA = board certified assistant behavior analyst, BCBA-D = board certified behavior analyst-doctoral, RBT = registered behavior technician.

https://jkms.org
Seoul has an estimated number of 28,544 children and adolescents with ASD (ages < 18 year-old), in comparison to 20,383 in Massachusetts (ages < 18 year-old). In Seoul, there is a total of 29 special education schools, of which six are schools for the blind and deaf. In Massachusetts, there is a total of 167 special education schools, of which seven serve students who are blind, eight serve students who are deaf, and 38 identify themselves as specifically serving those with ASD. Forty-nine (29.3%) of the special education schools in Massachusetts are residential programs. Additionally, there are 25 collaborative programs that provide special education or vocational programs in schools within a specified region. In Seoul, among mainstream schools, 67 of 906 kindergartens, 264 of 602 elementary schools, 192 of 388 middle schools, and 204 of 326 high schools have the capacity to provide special education classes with a specially trained teacher and also allow for partial inclusion. In Massachusetts, there are 1,113 elementary public school programs, 330 middle/junior high school programs, and 404 secondary (high school) programs, and all schools have the capability to provide special education services. Currently, 40.4% of students with ASD in Massachusetts are in full-inclusion placements (ages 6–21 years; 2016), just over 14% of students are in partial inclusion, 30.0% are in substantially separate programs, and 14.8% have been placed in out-of-district specialty programs.

In terms of clinicians, in Seoul, there are 731 psychiatrists including 191 child and adolescent psychiatrists (CAPs) and 1,236 pediatricians, including 50 child neurologists in 2018. In Massachusetts, there are 2,030 psychiatrists, including 475 CAPs and 2,081 pediatricians, with 51 specially trained as developmental-behavioral pediatricians, and 171 child neurologists. Seoul has 700 psychologists (PhD and PsyD), whereas Massachusetts has 6,168. Seoul also has 68 Board Certified Behavior Analysts (BCBAs)/Board Certified Assistant Behavior Analysts (BCABAs)/Board Certified Behavior Analysts-Doctoral (BCBA-Ds) and 12 Registered Behavior Technicians (RBTs), whereas Massachusetts has 2,064 BCBAs/BCABAs/BCBA-Ds and 796 RBTs.

Table 2 shows comparison of early therapeutic interventions for ASD in Seoul and Massachusetts. The number of these therapeutic interventions are provided in a range of < 5, 5–10, 10–15, 15–30, 30–50, 50–100, 100–150, 150–200, or > 200 in the Table 2 as it is deemed nearly impossible to be able to report an exact or updated count to date. Despite its immense population, Seoul has fewer available services for some of the early therapeutic interventions for ASD, including the most evidence-based treatment, Applied Behavior Analysis (ABA). However, other interventions, such as the Social Communication/Emotional Regulation/Transactional Support (SCERTS) Model, Treatment and Education of Autistic and Communication Handicapped Children (TEACCH), occupational therapy, sensory integration, social skills therapy, are present in fairly comparable numbers.

Table 3 shows a comparison of services/programs for ASD by age group in Seoul and Massachusetts. For school-age children with ASD, both Seoul and Massachusetts have parent training, an at-school program, and services for transition to adulthood. For instance, special education schools in Seoul operate weekly at-school programs such as art and sport activities. As part of transition to adulthood services, those special schools in Seoul allow students with developmental disorders including ASD to start taking transitional level courses in a major of their choice. However, Seoul currently does not have identifiable daily after-school programs or therapeutic (residential) schools. In Massachusetts, students in need of special support/education are allowed to remain in the school system until the age of 22 years. For college-age
individuals with ASD, Massachusetts has on-campus services/programs and employment assistance programs, whereas Seoul does not. For adults, both places have available social skills groups, day (rehabilitation) programs, employment services, recreational services, and medical/dental services, but Seoul does not have residential or transportation services specialized for ASD.

Table 4 presents a comparison of various levels of intensity of care for child and adolescent psychiatric patients in Seoul and Massachusetts. Massachusetts offers multiple levels of intensity of care for child and adolescent psychiatric patients, ranging from in-home services to outpatient to partial hospital to residential to inpatient and to long-term inpatient programs. Although this broad continuum of care is not specific to patients with ASD, it is noteworthy as patients with ASD often get treated in these facilities. Currently, there is no inpatient level of care program specialized for patients with ASD in either Massachusetts or Seoul. In Seoul, only acute inpatient services and outpatient clinics are available. There are only two psychiatric inpatient units specialized for child and adolescent Seoul, whereas other

### Table 2. Comparison of early therapeutic interventions for ASD in Seoul, Korea and the Commonwealth of Massachusetts

| Intervention                          | Seoul   | Massachusetts
|---------------------------------------|---------|-------------------|
| ABA/discrete trial training           | 30–50   | 150–200          |
| Pivotal response treatment            | 5–10    | Data unavailable |
| Verbal behavior therapy               | 5       | 30–50            |
| Early start denver model              | < 5     | Data unavailable |
| Floor time or DIR                     | 5–10    | 15–30            |
| Relationship development intervention | Unavailable | < 5            |
| SCERTS model                          | < 5     | < 5              |
| TEACCH                                 | 5–10    | 5–10             |
| Augmentative and alternative          | 15–20   | 50–100           |
| communication                         |         |                   |
| Picture exchange communication        | 10–15   | 30–50            |
| Occupational therapy                  | 30–50   | 50–100           |
|                                      | (excluding specialized facilities for cerebral palsy without ID or ASD) | |
| Sensory integration                   | 50–100  | 30–50            |
| Social skills therapy                 | 100–150 | 100–150          |
| Speech and language therapy           | 30–100  | 50–100           |

ASD = autism spectrum disorder, ABA = applied behavior analysis, DIR = developmental, individual difference, relationship-based model, ID= intellectual disability, SCERTS = social communication/emotional regulation/transactional support, TEACCH = treatment and education of autistic and communication-handicapped children.

### Table 3. Comparison of services/programs for ASD by age group in Seoul, Korea and the Commonwealth of Massachusetts

| Age          | Program                                      | Seoul                                    | Massachusetts
|--------------|----------------------------------------------|------------------------------------------|-------------------|
| School age   | After-school program                         | Several, once-a-week programs           | Available         |
|              | Parent training                              | Available                                | Available         |
|              | At-school program                            | Available (at special education schools) | Available         |
|              | Therapeutic (residential) school             | Unavailable                              | Available         |
|              | Transition to adulthood service              | Available (at special education schools) | Available         |
| College age  | On-campus                                    | Unavailable                              | Available         |
|              | Employment services                          | Several, at special education schools or specialized centers | Available         |
| Adult        | Social skills group                          | Available                                | Available         |
|              | Day (rehab) program                          | Available                                | Available: age > 22 years |
|              | Employment services                          | Available (none at hospitals; mainly at Community Rehabilitation Centers) | Available: age > 22 years |
|              | Residential services (e.g., group home)      | Group homes (supervised, not specialized for ASD) | Available: age > 22 years |
|              | Transportation services                      | Taxi for handicapped person              | Available: age > 22 years |
|              | Recreational/leisure services                | Available (mainly disabled welfare centers) | Available: age > 22 years |
|              | Health and dental services                   | Available (mainly private centers)       | Available: age > 22 years |

ASD = autism spectrum disorder.
psychiatric inpatient units include both adults and youth. Acute or long-term residential or day programs and intensive outpatient programs are not available in Seoul.

In terms of additional services, there are various avenues in Massachusetts through which patients and families can seek assistance related to care and support for ASD-related issues, such as state agencies, advocates, attorneys, family grant opportunities, financial planning, and guardianship. Currently, however, these specialized additional services for ASD are not readily available in Seoul.

**DISCUSSION**

The current study provides an overview of similarities and differences in services for ASD between Seoul, Korea and Massachusetts, USA. Although Seoul and Massachusetts are comparable in many aspects, including education, economy, and general quality of healthcare, Massachusetts has a significantly higher number of interventions, services, and programs, available for individuals with ASD than does Seoul. Our comparative findings can help to highlight areas to target to improve care for individuals with ASD in Seoul.

First of all, Seoul has a significant need for enhanced early identification and intervention services, and currently does not have any regulation or policies overseeing provision of such services. In the US, the Children’s Health Act34 authorized the CDC to monitor the prevalence of ASD in multiple areas of the country, and the CDC reports the prevalence of ASD every other year. A Korean law, the Act on Guarantee of Rights of and Support for
Persons with Developmental Disabilities, states that the Minister of Health and Welfare shall conduct a fact-finding survey on persons with developmental disabilities every three years. However, this survey is not specific for ASD and does not investigate the prevalence or the service utilization. Moreover, our estimated prevalence shows that less than one fifth of children and adolescents with ASD in Seoul is registered in National Registry for ASD. Such a significant discrepancy could stem from multiple factors including: 1) under-diagnosis of ASD, 2) ongoing fear of stigma, 3) lack of understanding among patients and families about potential benefits of registering for national registry, or 4) sense of few additional benefits for registering in Korea. Lessons could be learned from successful national registry models in other countries (e.g., Swedish National Patient Registry) that has allowed researchers access to population-based longitudinal data of their citizens. Various types of key studies could be performed utilizing such population-based longitudinal data. For example, precise and up-to-date epidemiological data would be essential for discovering areas of needs, advocating for relevant policies, and/or allocating available resources to the given population in the country. For early identification of ASD, infant and child health checkups at 4th–6th, 9th–12th, 18th–24th, 30th–36th, 42nd–48th, 54th–60th and 66th–71st month are provided by the National Health Insurance (NHI) of Korea. However, there is no specialized law or policy for early intervention for ASD in Korea. Thus, the number of available early intervention programs is quite low despite the estimated high prevalence of ASD in children in Seoul. Moreover, there is a relatively larger number of facilities that offer interventions that currently are not evidence-based, such as sensory integration therapy, compared to interventions supported by rigorous research, such as applied behavioral analysis.

The difference in the number and diversity of early intervention services and treatment facilities could be related to the difference in the insurance system and social support. Korea has a single NHI system which is compulsory and covers 97% of the population. While Korean National Health Insurance (K-NHI) covers most medical disorders and the patient’s co-pay is much lower than that in the US, K-NHI does not cover educational or behavioral intervention for ASD. As a result, the amount of early educational or behavioral intervention services, especially hospital-based intervention services, is much lower in Korea compared to the US, and parents often are solely responsible for paying the treatment fees themselves. In Massachusetts, An Act Relative to Insurance Coverage for Autism (ARICA), a state law signed in 2010, mandates that private health insurance plans pay for services required for diagnosis and treatment of ASD that include but are not limited to ABA, psychiatric care, and social skills groups. In 2015, the Autism Omnibus Act required the public health insurance plan, MassHealth (comprised of Medicaid and Children’s Health Insurance Program), to cover ABA services for individuals under the age of 21 years. A 2014 study estimated that in the U.S., the lifetime economic cost would measure up to $2.4 million (USD) to care for a patient with ASD and IDD, and $1.4 million for ASD alone, which was largely derived from required special education and challenged parent employment/productivity. There is currently no study about economic cost for ASD in Korea, but ASD is known to cause great disease burden in Korea as well. Moreover, it can be assumed from the U.S. study that the economic burden for supporting a patient with ASD in Seoul would also be too challenging for an individual family to carry without any governmental or community support for ongoing needs of special education/services and lost parent employment/productivity. An increase in the coverage for educational and behavioral interventions, expansion of public services for evidence-based interventions, and appropriate treatment coordination and case managements is surely needed in Seoul, Korea.
Moreover, while nearly all public schools have some therapeutic capability in Massachusetts, students with ASD are not identified or followed within the school system and there is a significant lack of school-based services for ASD in Seoul. For instance, few schools offer opportunities for partial inclusion, most schools do not, and there is no known full inclusion program in Seoul. Partial or full inclusion of students with ASD is known to help students increase social initiation and enhance social skill acquisition and generalization. In addition to the scarcity of inclusion programs, there is also a concern for the lack of regulation for such programs in Seoul. In the U.S., per the Individuals with Disabilities Education Act (IDEA), all children are entitled to a “free and appropriate public education” (FAPE). They are also entitled to receive education in the “least restrictive environment” (LRE). Thus, all schools should have the capability to provide some special educational supports. However, in cases when the local school is unable to provide the appropriate services within their district, the student may be placed outside of their local school district into a collaborative program where neighboring towns or regions share resources to provide services for children with special needs. If the local district and collaborative program are unable to address the student’s needs in a satisfactory manner, the student then might be placed in a private, out-of-district school setting. Similar laws and educational policies for the inclusion of students with ASD and school-based psychosocial treatment are called for in Seoul.

Furthermore, only a few school-age children with ASD in Seoul receive services about once a week on average, which are mostly based in hospitals or local private centers run by clinical psychologists, as there are almost no school- or community-based services in Seoul. Even for the available services, the services are sparse considering the estimated number of individuals with ASD in Seoul. There is a significant lack of therapeutic facilities and specialists in schools in Seoul. In addition, despite the shortage of special education schools in Seoul, the government often faces significant challenges in building new special education schools because of resistance from local residents, also known as the “Not In My Back Yard” (N.I.M.B.Y) phenomenon. A new law and/or policy for school-based intervention for school-age students and a public campaign for increasing awareness of ASD are needed.

Finally, there is currently a significant lack of services and programs for the transition to adulthood, including access to higher education such as college, or vocational training for individuals with ASD in Seoul, despite the Act on Guarantee of Rights of and Support for Persons with Developmental Disabilities which describes the assistance in employment and vocational training as part of lifelong education. In Massachusetts, individuals are required by IDEA to start planning for transition to adulthood by the age of 14 years, frequently in collaboration with their IEP teams that are familiar with personal challenges and needs. Transition to adulthood, employment, and academic and non-academic services for college students which can be applied to most adults with ASD, are needed in Seoul.

This study has a number of limitations: 1) the searched data were neither exhaustive nor systematic, 2) data were acquired from various sources, and all were not fully up to date, 3) methodologies for some of the data sources could not be verified, which all raises concerns for missing or incomplete data, and 4) Seoul and the commonwealth of Massachusetts were not meant to represent Korea and the USA, respectively. However, the descriptive results from the current study raise concerns about the limited availability of services for individuals with ASD and their families across settings in Seoul (e.g., disproportionate lack of funding, low public awareness), in comparison to Massachusetts. Such significant gaps highlight potential areas for investment and suggest future directions for growth and improvement.
in caring and providing for those with ASD in Seoul. Interestingly, despite being very resourceful in most areas of service for individuals with ASD, Massachusetts currently does not have a specialized inpatient unit for those with ASD experiencing significant behavioral issues. Additional comparison studies including other developed countries (e.g., Thailand, Japan, Taiwan, and others.) within Asia or regions (e.g., North America, Northern Europe, and others.) could also guide clinicians and policy-makers in efforts to improve the quality and provision of available services for ASD within their community.

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