



**CENTER FOR GLOBAL  
HEALTH DELIVERY–DUBAI**  
HARVARD MEDICAL SCHOOL

# PROCEEDINGS

## Systems of Care for Autism Spectrum Disorder: A Global Perspective



**IN COLLABORATION WITH**



# **Systems of Care for Autism Spectrum Disorder: A Global Perspective**

## **Workshop Proceedings**

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**March 30 – April 1, 2017**

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International Standard Book Number  
ISBN-10: 1-944302-02-6  
ISBN-13: 978-1-944302-02-3

Suggested citation: Systems of Care for Autism Spectrum Disorder: A Global Perspective. Proceedings of the Harvard Medical School Center for Global Health Delivery–Dubai. 2017, Dubai, United Arab Emirates.

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# 1 Introduction to Autism Spectrum Disorder and Systems of Care

## 1.1 EXECUTIVE SUMMARY

Autism spectrum disorder (ASD) is a heterogeneous and complex neurodevelopmental disorder that is characterized by impairments in social communication and associated behaviors. The rising population prevalence of ASD can constitute a significant public health concern with recent estimates at approximately 1.5 to 2%. ASD significantly impacts the affected individuals and their families' societal and economic burden, which, in turn, can perpetuate their social exclusion. Given the heterogeneity of ASD and complexity of clinical presentation, affected individuals have variable needs at different developmental stages that cut across different systems including, but not limited to, the healthcare, social, and educational systems. An isolated, narrow view of ASD may result in delays of access to treatment, lack of integration and coordination of services, thereby risking duplication of services and imposing an undue burden on affected individuals and families to navigate a fragmented system. It is therefore necessary to approach ASD from a comprehensive system of care perspective that can promote integrated services resulting in a seamless journey for affected individuals and their families. Issues related to a lack of an integrated and comprehensive view of ASD is a common problem shared by professionals across different countries. Hence, the conference "Systems of care for ASD: A global perspective" was held to shed the light on this issue and provide a platform to share experiences and develop recommendations towards developing a comprehensive system of care for ASD that would result in easier access, decreased obstacles, and improved outcomes. In addition to the social benefits, economic benefits to a comprehensive and integrated system of care were highlighted that provide efficient, coordinated, accessible, continuous culturally competent care. During the conference, specific aspects related to systems of care for autism were discussed including surveillance early screening, diagnostic evaluations, early intervention, as well as transition to other educational and social services. Experiences were shared by experts from different countries including the United Arab Emirates, Saudi Arabia, Qatar, Bahrain, Tunisia, Lebanon, Bangladesh, and Pakistan, Australia, and the United States of America. In summary, the conference highlighted the importance of a comprehensive system of care approach for ASD, and the important need for coordinating services across different sectors. Detailed recommendations were included at the end of the report.

## 1.2 ORGANIZATION OF THE CONFERENCE

From March 30-April 1, 2016 the The conference was chaired by Dr. Ammar Albanna, and co-chaired by Dr. Hesham Hamoda and Dr. John Fayyad. Al Jalila Children's Specialty Hospital, the only hospital in the United Arab Emirates solely dedicated to the care of children, organized a first of its kind conference on autism spectrum disorder (ASD): "Systems of Care for Autism Spectrum Disorder: A Global Perspective." The conference was hosted in collaboration

with the Harvard Medical School Center for Global Health Delivery–Dubai, the Eastern Mediterranean Association for Child and Adolescent Psychiatry and Allied Professionals (EMACAPAP), the International Association for Child and Adolescent Psychiatry and Allied Professionals (IACAPAP), and the Section on Child and Adolescent Psychiatry of the World Psychiatric Association. The conference was chaired by Dr. Ammar Albanna, and co-chaired by Dr. Hesham Hamoda and Dr. John Fayyad. The objective of the conference was to address priorities with respect to the development of evidence-based based child

mental health for the care of children with Autism Spectrum Disorder (ASD). While the number of child mental health initiatives is encouraging, multiple challenges persist in establishing effective and integrated systems of care for children with mental health issues and ensuring the utilization of evidence-based approaches that are appropriately tailored to the local context. It is therefore crucial to learn from global experiences in order to establish innovative models for child mental health care. One of the priorities with respect to mental health services is Autism Spectrum Disorder (ASD), but meeting the complex needs of children, adolescents, and families facing ASD poses significant challenges to healthcare systems. The aim of the conference was to develop recommendations to serve as a roadmap towards developing and improving systems of care for ASD at the national, regional, and global levels. As part of its mission, Al Jalila Children's Specialty Hospital aims to develop a best-practices document on systems of care for ASD; the three-day conference was a first step towards achieving this objective.

The conference was held March 30, March 31, and April 1 at the Mohammed Bin Rashid University of Health Sciences in Dubai, United Arab Emirates. The conference featured presentations by global experts in ASD, as well as presentations that provided regional perspectives on developing systems of care for ASD. The conference also organized facilitated discussion sessions among panelists and participants. The day after the conference, a group of global, regional, and national experts in ASD participated in a planning workshop focusing on key elements required for the development of successful systems of care for ASD in Dubai, and regionally.

## 1.3 ORGANIZATION OF THE PROCEEDINGS

This report has been commissioned to capture the conference presentations and discussions. The report is organized into six chapters: Chapter 1 introduces ASD and systems of care; Chapter 2 covers identification, screening, and early detection of ASD; Chapter 3 focuses on diagnosis and comprehensive assessment of ASD; Chapter 4 considers early intervention and treatment of ASD; Chapter 5 provides regional perspectives on developing ASD services and systems of care; and Chapter 6 summarizes key recommendations selected by the conference planning committee.

## 1.4 OVERVIEW OF AUTISM SPECTRUM DISORDER

### 1.4.1 Essential Elements of Autism Spectrum Disorder

Dr. Ammar Albanna<sup>1</sup> introduced Autism Spectrum Disorder (ASD) as a heterogeneous and complex neurodevelopmental disorder defined by (A) impairments in social communication and (B) patterns of restricted, repetitive behaviors or interests.<sup>2</sup> The estimated prevalence of ASD has increased significantly in recent years (Figure 1). In 2014, the CDC reported an ASD prevalence of 1 in 68 children;<sup>3</sup> however some studies have reported higher prevalence rates of up to 2-3 %<sup>4</sup>. A 2014 report by the Centers for Disease Control (CDC) stated that males are 4.5 times more likely to be diagnosed with ASD than females,<sup>5</sup> though epidemiologic studies suggest that the ratio may be lower in population-based samples as opposed to clinical samples.

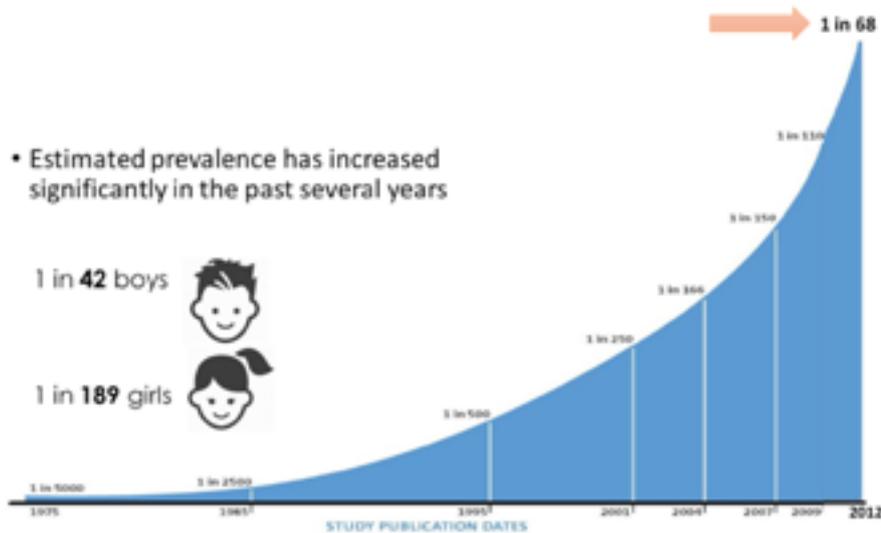
1 Ammar Albanna, MD FRCPC IFAPA, Al Jalila Children's Specialty Hospital Mohammed Bin Rashid University for Health Sciences (MBRU), Dubai, United Arab Emirates (UAE)

2 American Psychiatric Association, Diagnostic and statistical manual of mental disorders (DSM)-5, 2013

3 Centers for Disease Control and Prevention *MMWR* 2014

4 Prevalence of Autism Spectrum Disorders in a Total Population Sample Young Shin Kim, Bennett L. Leventhal, Yun-Joo Koh, Eric Fombonne, Eugene Laska, Eun-Chung Lim, Keun-Ah Cheon, Soo-Jeong Kim, Young-Key Kim, HyunKyung Lee, Dong-Ho Song, and Roy Richard Grinker *American Journal of Psychiatry* 2011 168:9, 904-912

5 Centers for Disease Control and Prevention *MMWR* 2014

**Figure 1. ASD prevalence**

Source: *Autism Speaks 2017*, with modifications based on data from CDC MMWR 2014

### 1.4.2 History of Autism Spectrum Disorder

Dr. Bennett Leventhal<sup>4</sup> traced the evolution of the concept of ASD over time. Although the syndrome was formally defined relatively recently, ASD has existed for as long as there have been people. Around the turn of the 19<sup>th</sup> century, the French psychologist Jean Marc Gaspard Itard published his account of attempting to educate the “Wild Boy of Aveyron,” an adolescent boy who was discovered living in the wild; he never progressed beyond extremely limited language and social skills. Leventhal posited that this may be the first scientific depiction of ASD. Of course, there have been reports of feral children and adults in folklore and “clinical” literature for millennia. In 1943, Leo Kanner published a seminal work entitled “Autistic Disturbances of Affective Contact” in which the term “autism” was used for the first time to describe the syndrome.<sup>56</sup> In a 1971 paper, he published the results of a longitudinal study of eleven people with symptoms of autism that he followed since childhood, beginning in 1938. Kanner reported that by 1971, the eleven

individuals had varying levels of function and most ended up in residential care.<sup>7</sup>

Through the 20<sup>th</sup> century, psychologists postulated a range of theories about autism, including the unfounded theory that the fault lay with parents (mainly mothers) who did not properly rear their children. Leventhal explained that parents who resented the stigma around ASD and the theory of parental blame began to organize and lobby at the local and national level, forming the National Society for Autistic Children (NSAC) in the 1970s. NSAC created its own diagnostic criteria to define the syndrome in 1977:

- Disturbed rate and/or sequence of development
- Disturbed response to sensory stimuli
- Disturbed speech/language and cognitive development
- Disturbed quality to relate appropriately to people, events, and objects<sup>8</sup>

Leventhal noted that NSAC’s diagnostic criteria are very similar to contemporary

4 Bennet Leventhal, MD, Professor, Department of Psychiatry, University of California – San Francisco, San Francisco, CA

5 Kanner L *Nervous Child* 1943.

6 Previously the term “autism” had been used to describe a symptom of schizophrenia.

7 Kanner L J *Autism Child Schizoph* 1971.

8 Ritvo *Journal of Pediatric Psychology* 1977.

diagnostic criteria that serve as the basis for Diagnostic and Statistical Manual for Mental Disorders 5<sup>th</sup> Edition (DSM-5).<sup>9</sup> ASD is understood today as a disorder that is marked by deficits in social communication and interaction coupled with restricted and/or repetitive patterns of behaviors that are present in early childhood and impair everyday functioning. Much of the general public is now broadly familiar with ASD, he observed, due to its burgeoning portrayal in movies and other forms of popular culture. However, he cautioned that characterizations of ASD in the media may fail to capture the nuances of the condition, creating a false sense of understanding among the public.

### **1.4.3 Clinical Presentation of Autism Spectrum Disorder**

According to DSM-5, explained Leventhal, ASD is one of twenty types of neurodevelopmental disorders (NDD).<sup>10</sup> Almost all forms of ASD, NDD, and intellectual disability (ID) are syndromes, characterized by a group of symptoms that tend to cluster together and

share a common natural history and course. In contrast, diseases are syndromes for which there is a known etiology and/or a known pathophysiological process. He explained that ASD/ID/NDD are heterogeneous in that not all symptoms are manifest in all patients and many symptoms are shared with other disorders. The etiologies of ASD/ID/NDD are as complex as their complex clinical phenotypes and presentations, because their pathologic processes are yet unknown and symptom presentation is heterogeneous. Leventhal explained that NDDs including ASD are similar to most other medical conditions, such as diabetes, asthma, hypertension, and atherosclerotic cardiovascular disease. In ASD, as with any other syndrome, such as hypertension, the medical profession (as well as affected individuals and families) arbitrarily sets a given point that demarcates risk or impairment, and therefore, merits intervention. To obtain funding for interventions for a medical condition, syndromes require a diagnostic label, a measurement of impairment and the availability of evidence-based interventions.

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<sup>9</sup> The Diagnostic and Statistical Manual of Mental Disorders (DSM) provides a common language by which clinicians, researchers, and public health officials communicate about mental disorders. The fifth revision (DSM-5) was published in May 2013. (American Psychiatric Association, 2013).

<sup>10</sup> Intellectual Disability (ID) (Intellectual Development Disorder); Global Development Delay; Unspecified Intellectual Disability (Intellectual Developmental Disorder); Language Disorder; Speech Sound Disorder; Childhood-Onset Fluency Disorder (Stuttering); Social Pragmatic Communication Disorder (SCD); Unspecified Communication Disorder; Autism Spectrum Disorder (ASD); Attention Deficit Hyperactivity Disorder (ADHD); Other Specified Attention-Deficit Hyperactivity Disorder; Unspecified Attention-Deficit Hyperactivity Disorder; Specific Learning Disorder; Developmental Coordination Disorder; Stereotypic Movement Disorder; Tic Disorder; Other Specified Tic Disorder; Unspecified Tic Disorder; Other Specified Neurodevelopmental Disorder; Unspecified Neurodevelopmental Disorder

**Box 1-1: ASD as a syndrome**

In response to a question about construing ASD as a disease versus an extension of normality, Leventhal clarified that he would consider ASD a syndrome, defined as a group of symptoms that tend to cluster together and share a natural history, whereas a disease is a syndrome for which we know the etiology or pathophysiology or both. Following this definition, ASD is a syndrome that has a spectrum and in this sense, similar to many other medical syndromes. He drew a comparison with Hypertension, as the cutoff for requiring intervention has been arbitrarily set for individuals at risk or with hypertension. Similarly, along the spectrum when an individual with ASD becomes impaired crosses the boundary of requiring services. He does not consider it a useful discussion to say that individuals with ASD are typical or not typical, but rather when do they require services. Leventhal contended other disorders could also be considered NDDs, including: OCD, eating disorders, mood disorders, bipolar disorder, major depressive disorder, substance abuse, schizophrenia, trauma related disorders, epilepsy, and Alzheimer's Disease.

### 1.4.3.1 Clinical definitions and Classifications of Autism and Autism Spectrum Disorder

Leventhal explained that all of ASD's constituent disorders share similar characteristics, such as the two "Ds": delay and deviations of behavior. Impairment in the domain of social development (joint attention, theory of mind, and reciprocity) are most prevalent, but impairments in communication development are common, as are restricted, repetitive, and stereotyped patterns of interests and activities. The presence of ASD signs and symptoms in a person with ASD tends to be consistent over time. Many symptoms persist over time – such as lack of social reciprocity, language abnormalities, restrictive and repetitive behaviors, and insistence on sameness – although some symptoms may decrease – such as stereotypies and problems with visual regard. Most individuals with an ASD improve over time, especially with proper interventions.

The 10<sup>th</sup> revision of the World Health Organization (WHO) diagnostic manual, the International Statistical Classification of Diseases and Related Health Problems (ICD-10), and the 4<sup>th</sup> edition of the Diagnostic and Statistical Manual (DSM-IV-TR)

by the American Psychiatric Association (APA) provide similar characterizations of autism and related disorders, under the category of Pervasive Developmental Disorder (PDD), with virtually identical diagnostic criteria:

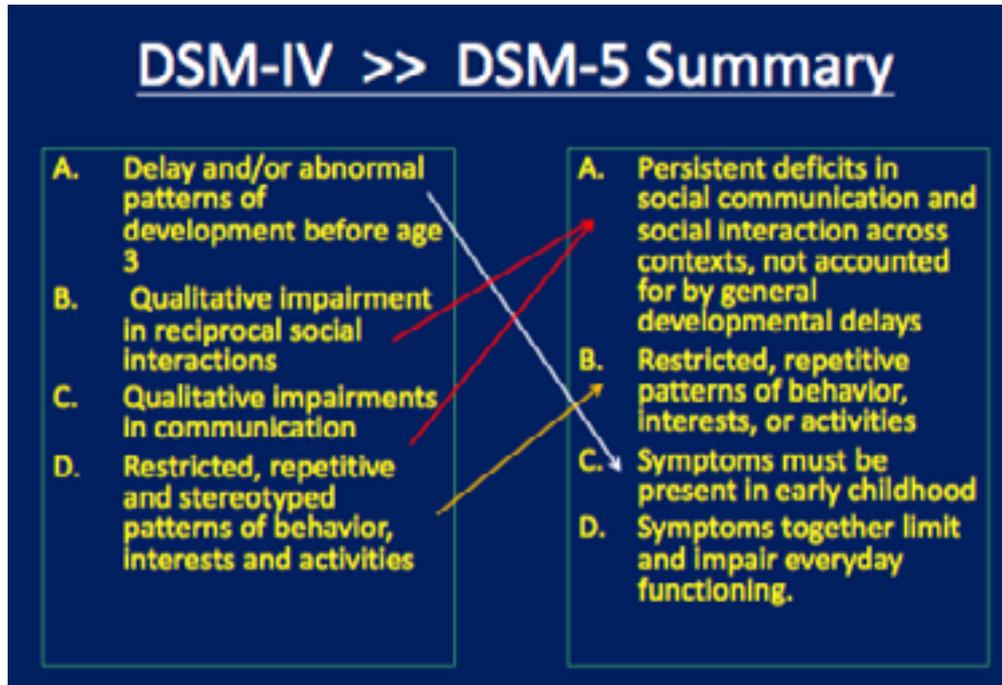
- Delay and/or abnormal patterns of development before age 3
- Qualitative impairment in reciprocal social interactions
- Qualitative impairments in communication
- Restricted, repetitive and stereotyped patterns of behavior, interests, and activities

Leventhal argued that that there has been little scientific evidence to support the distinctions between the discrete DSM-IV subtypes of autism, especially Autistic Disorder, Asperger Syndrome, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). This is complicated by the fact that PDD-NOS is often applied to children who have some symptoms of autism but who do not fulfill the criteria for Asperger Syndrome or another ASD. Since there are no identified genetic patterns, neuroimaging data, or other data that can be

used to discriminate among subtypes, they have been combined under the category of autism spectrum disorder (ASD). He noted that this issue reflects the heterogeneity of

ASD itself. When the DSM-5 was introduced, the diagnostic criteria for ASD were re-defined (Figure 2):

**Figure 2. Comparison of DSM-IV and DSM-5 clinical definitions of ASD**



Source: Leventhal presentation at the “Systems of Care for Autism Spectrum Disorder: A Global Perspective” conference hosted by Al Jalila Children’s Specialty Hospital in Dubai, in collaboration with the HMS Center for Global Health Delivery–Dubai, March 31, 2017

Leventhal noted that the DSM-5 eliminated PDD-NOS as a subtype, but retained Asperger’s Syndrome and added Social Communication Disorder (SCD), an impairment of pragmatics diagnosed based on difficulty using verbal and nonverbal communication in social contexts. A diagnosis of SCD requires ruling out ASD.

The DSM-5 also included specifiers for determining severity of ASD (although there is no standard measure for severity):

- Age of first concern
- With or without loss of established skills
- With or without accompanying intellectual impairment

- With or without accompanying structural language impairment
- Associated with a known medical or genetic condition or environmental factor
- Associated with another neurodevelopmental, mental, or behavioral disorder
- Severity of symptoms

Severity specifiers relate to social and communication impairment as well as restricted interests and repetitive behaviors (Level 1: requiring support; Level 2: requiring substantial support; Level 3: requiring very substantial support).

Leventhal explored the concept of the autism spectrum, noting the continuity of

symptoms ranging from mild to severe. Four elements generally constitute the spectrum: idiosyncratic behaviors, language capacity, quality of social skills, and cognitive functioning. Where a specific individual falls along each dimension of the spectrum correlates to his/her level of functioning. He drew an important distinction between individual variability in skill level with respect to specific elements and the concept of functioning as understood in the more adaptive sense (i.e., relative to so-called “neurotypical” people). The spectrum or axes of ASD, according to Leventhal, include the following:

- Many ASD behaviors ↔ fewer ASD behaviors
- Poor or no language ↔ fluent language
- Poor social skills ↔ good social skills
- Lower cognitive function ↔ higher cognitive function

#### 1.4.3.2 Comorbidity

Leventhal explained that in the DSM-5, ASD can be associated with other neurodevelopmental, mental, and/or behavioral disorders (i.e., there are no exclusionary comorbidities). Examples of commonly occurring comorbidities include ADHD (which had been specifically excluded as a comorbid diagnosis in DSM-IV), mood disorder, anxiety disorder, and OCD. Dr. Kerim Munir noted that 56% of children with ASD also have significant adaptive and cognitive functioning deficits, including both intellectual disabilities (ID) and intellectual and developmental disabilities (IDD). He reported that according to CDC prevalence data, 44% of children with ASD have co-occurring ID/IDD, 44% have ASD without ID/IDD, and 12% of children with ASD have borderline intellectual/adaptive functioning. Dr. John Fayyad cited long-term studies showing that ASD and Asperger’s patients may face an elevated risk of developing psychotic disorders as they age. Leventhal recommended continuously reassessing for comorbidities, because they are not static. In

fact, as epidemiological studies are conducted using population-based samples rather than clinical samples, the profile of comorbidity is changing quite significantly. For instance, studies show less comorbidity of ID in patients with ASD. Furthermore, children can develop behavioral issues and psychosis as he or she ages, leading to possible misdiagnosis of ASD in children with schizophrenia, for example. He speculated that better epidemiologic studies and improved understanding of the genetics of ASD may reveal genetic overlap of ASD with many other disorders.

#### 1.4.4 Epidemiology: Global Prevalence and Burden of Autism Spectrum Disorder

##### 1.4.4.3 Prevalence Studies of Autism Spectrum Disorder

Valsamma Eapen reported that worldwide, 23% of children aged 2 to 9 years are at risk of developmental and/or behavioral disorders, with 15-17% having learning or related disabilities and 1-3% having a major disability. Kerim Munir noted that around 52 million people were living with ASD worldwide as of 2010. According to CDC data between 1988 and 2010, there was an increase in the prevalence rate of more than ten-fold in the United States.

Munir noted significant disparities in ASD prevalence in children (aged 8 years) across gender and race; CDC data indicate ASD prevalence is higher among male children, Caucasian children, and children identified in combined education and health settings (through systems of care in place in some US states). Data show greater overlap of ASD with intellectual disability among black Americans and Hispanic Americans.

Dr. Aliya Naheed provided an overview of the burden of ASD in Asia:

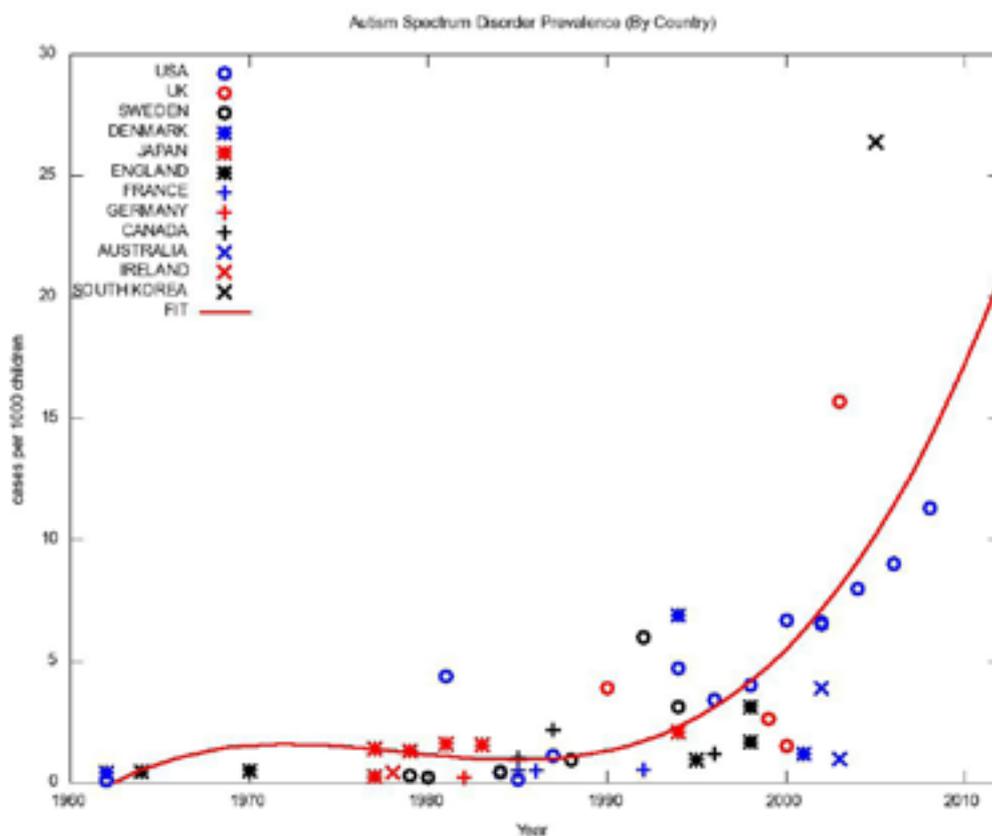
- Indonesia: 11.7 cases per 10,000
- China: 11.0 cases per 10,000
- Hong Kong: 7.9 cases per 10,000
- Iran: 6.26 cases per 10,000

She noted that the prevalence of common mental disorders is increasing worldwide. Globally, rates of depression and anxiety have increased 50% from 1990 to 2013. Mental disorders account for 30% of the global non-fatal disease burden and 32.4% of years lived with disability (YLDs). The number of disability-adjusted life years (DALYs) attributable to mental illness is comparable to cardiovascular and circulatory diseases, with

ASD alone accounting for more than 58 DALYs, she reported.

Leventhal reported that in 1985, the US prevalence for autism was around 1/2500. By 1995, it increased to around 1/500. Newer estimates of ASD prevalence range from 1/45 to 1/88. Prevalence studies of ASD by country reveal a similarly steep increase in prevalence since 1990 (Figure 3):

**Figure 3. Prevalence studies of ASD by country**



Source: John F. McGowan, 2018

Munir noted that 83% of all global ASD cases have been reported in high-income countries, although the majority of the world's population of children live in lower income countries. With the exception of China, there have been few population-based studies of ASD in low- and middle-income countries (LMICs). Regarding the lack of ASD studies in LMICs, Naoufel Gaddour noted that ASD is

a universal phenomenon and epidemiologic data (which are admittedly limited), show no evidence that ASD prevalence is different in any community in which it has been studied. Yet for many years, officials claimed that ASD did not exist in sub-Saharan Africa because so few people sought services, though this is not the case. Though ASD prevalence is considered relatively consistent context to

context, Leventhal warned that designing a responsive healthcare model is contingent upon knowledge of the burden and impact of disease at the national, regional and community levels. Munir emphasized that prevalence studies in LMICs require that tools and instruments be carefully translated and appropriately adapted to the local cultural context.

#### 1.4.4.4 Is there an autism epidemic?

According to Leventhal, the increasing range of prevalence across countries worldwide has fueled speculation that there is an “epidemic of ASD.” To explore whether this is actually the case, he drew important distinctions between incidence, point prevalence, and period prevalence. Point prevalence is the proportion of a given population having a particular condition or characteristic at a specific point in time. Period prevalence is the proportion of a given population having a particular condition or characteristic during a given period of time. Prevalence, the number of cases present in a population, is not the same as incidence, the number of new cases in a specific time period divided by the size of the population at risk. An epidemic is defined as a dramatic rise in incidence, yet prevalence can increase without an increase in incidence. Munir emphasized that sound epidemiology requires measuring incidence as well as prevalence. Leventhal noted that there have not yet been any incidence studies for ASD, in part because its initial presentation is gradual and there is not a discrete start to the disorder. This is complicated by the fact that it is difficult to attract funding for longitudinal studies. Leventhal reported that at least one incidence study is currently underway and should be reported in the next few years.

Both Munir and Leventhal emphasized that changes in prevalence are not necessarily due to biological or genetic factors, but can result from changes in the ways that children with ASD are identified and diagnosed. Leventhal explained that increases in the prevalence of ASD do not require corresponding changes in incidence. For example, changes in case

definitions and study design have had a direct impact on the increase in ASD prevalence, without altering incidence to the same extent. Leventhal attributed the increasing numbers of cases that are present worldwide to a multitude of converging factors, including:

- Diagnostic changes, including broadening of diagnostic criteria
- Better screening and diagnostic tools, which have improved the identification process
- Improved research methods
- Increased awareness about ASD among mental health providers, primary care, schools, media, and parents
- Increased access to services for people affected by ASD
- Legal access requirements
- Wider age range (previously, children were not diagnosed until entering school)
- Diagnostic switching (children receive better services if they are labelled autistic, so diagnosis of ASD increases)

Leventhal explained that the case definition used to diagnose ASD can substantially impact prevalence rates. He recounted that across studies, the reported mean prevalence can range from 0.038% (using Kanner’s criteria; n=6 studies) to 0.071% (using DSM-III criteria; n=8 studies) to 2.60% (using current DSM-5 criteria; n=1 study). Leventhal predicted that the increasing use of internationally agreed-upon “gold standard” assessment tools—the Autism Diagnostic Observation Schedule – 2 (ADOS-2) and the Autism Diagnostic Interview - Revised (ADI-R)—will help to stabilize estimates of prevalence. Leventhal provided an overview of prevalence estimates across different diagnostic methods (DSM-IV PDD, DSM-5 ASD, DSM-5 SCD) (Figure 4):

**Figure 4. Prevalence estimates across diagnostic methods**

	% DSMIV PDD	% DSM5 ASD	% DSM5 SCD	% DSM5 ASD+SCD
<b>Population</b>				
Total	2.64	2.20	0.49	2.69
GPS	1.89	1.46	0.49	1.95
HPG	0.75	0.75	0.00	0.76
<b>DSMIV PDD Subtype</b>				
Autistic Dis	1.04	1.03	0.001	1.04
Asperger	0.60	0.55	0.05	0.59
PDD-NOS	1.00	0.63	0.32	0.94

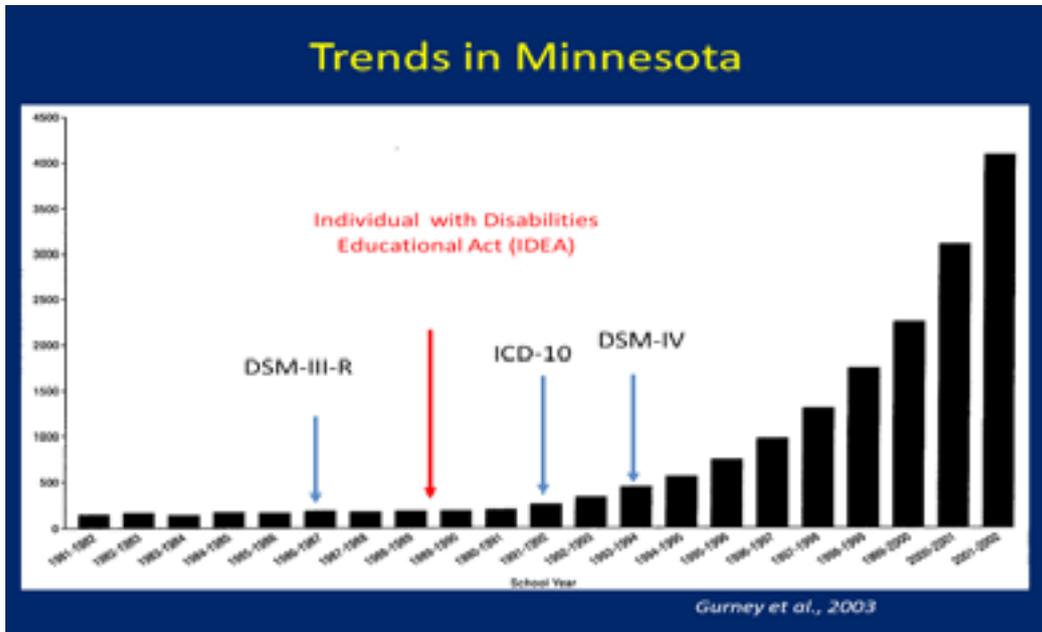
  

	Divergent Group n=22 (7.5%)
SCD	14
SCD + Other Psych Disorder	4
Other Psychiatric Disorder Only	5
No Diagnosis	0

Source: Leventhal presentation at the “Systems of Care for Autism Spectrum Disorder: A Global Perspective” conference hosted by Al Jalila Children’s Specialty Hospital in Dubai, in collaboration with the HMS Center for Global Health Delivery-Dubai, March 31, 2017

Leventhal further argued that data previously used to support the purported “ASD epidemic” actually reflects an uptake in service access and utilization. For example, for a time, many children with ASD in the United States were denied education because they were deemed too difficult to educate or accommodate, until a 1977 US law mandated that schools provide education for all children. According to data from California,

the number of persons with autism enrolled in services increased more than three-fold in the 15 years following the law’s enactment. There was a similar trend in Minnesota, after the implementation of the Individual with Disabilities Educational Act (IDEA), the introduction of the ICD-10, and the publication of the DSM-IV, which extended the breadth of diagnostic criteria for ASD (Figure 5):

**Figure 5. Trends in Minnesota**

Source: Leventhal presentation at the “Systems of Care for Autism Spectrum Disorder: A Global Perspective” conference hosted by Al Jalila Children’s Specialty Hospital in Dubai, in collaboration with the HMS Center for Global Health Delivery-Dubai, March 31, 2017; Gurney et al. *Arch Pediatr Adolesc Med* 2003

According to recent CDC data, between 2011-2013 and 2014 the prevalence for ID decreased from 1.27 to 1.10, while the prevalence of ASD increased from 1.25 to 2.24. Leventhal explained that the prevalence of ID did not decline. Instead, changes to the CDC’s questionnaire led to the capture of more ASD cases, thereby leading to fewer reported cases of ID.

Leventhal emphasized that a number of factors have together influenced ASD prevalence trends, including changes in diagnostic criteria, diagnostic tools, service utilization, study design, and legislation. It is critically important to consider all factors when calculating and interpreting epidemiological trends. For the most accurate prevalence estimates, it is important to include both clinical and non-clinical ASD populations in calculations, as many children do not present to health systems.

Leventhal commented on the impact of increased awareness about ASD across all forms of media (e.g., CDC – ASA Campaign in the USA (2005): “Learn the Signs. Act Early”), suggesting that changing public perceptions about autism increase the number of children with ASD who present to the health system. Gordon Harper suggested leveraging theater, art, social engagement, and the media to educate and promote awareness about ASD. For example, the popular children’s television program *Sesame Street* has recently introduced a character with ASD<sup>11</sup>. Leventhal reflected: “ASD is one of the most common chronic illnesses affecting childhood. It is not an epidemic. These children have always been there. We just didn’t look for them.”

#### 1.4.4.5 Non-Evidence based Etiological Hypotheses for ASD

Andrew Wakefield published a since-debunked and formally retracted study in 1998 that had catastrophic ramifications, noted

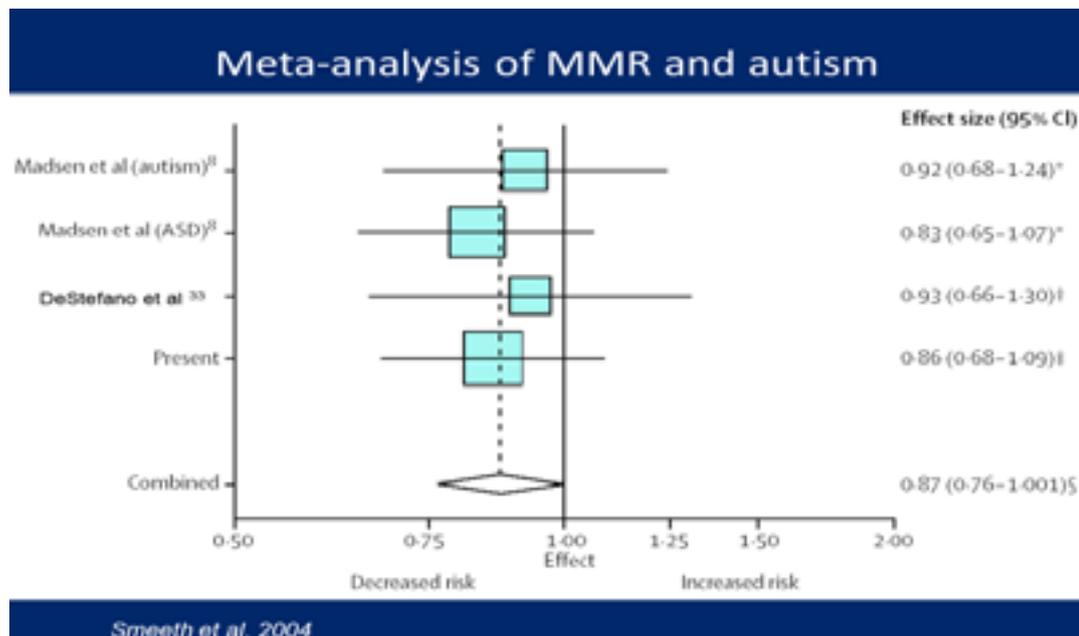
<sup>11</sup> <http://autism.sesamestreet.org>

Leventhal. He explained that Wakefield is a gastroenterologist with minimal training in child psychiatry and that Wakefield did not use established diagnostic methods in his study. Wakefield's study examined twelve children with ASD (he classified the disorder as Pervasive Development Disorder, or 'PDD') who were referred to him for treatment of gastrointestinal problems. The onset of ASD symptoms appeared to be near the time of the children's MMR vaccination, leading Wakefield to theorize that exposure to the MMR vaccine led to gastrointestinal dysfunction and conclude that ASD resulted from the passage

of MMR virus or vaccine products from the bowel to the brain.

Leventhal emphasized that there is absolutely no correlation between MMR vaccine prevalence and risk of ASD. MMR does not cause children to regress, nor does the mercury in vaccines cause ASD. Meta-analysis indicates that MMR vaccination is actually protective against ASD, not causal (Figure 6 – Boxes to the left of the line = no correlation):

**Figure 6. Meta-analysis of MMR and autism**



Source: Leventhal presentation at the “Systems of Care for Autism Spectrum Disorder: A Global Perspective” conference hosted by Al Jalila Children’s Specialty Hospital in Dubai, in collaboration with the HMS Center for Global Health Delivery-Dubai, March 31, 2017; Smeeth et al. *Lancet* 2004

Leventhal strenuously defended the critical life-saving importance of the MMR vaccine for measles, “a serial killer” that kills 900,000 people each year, with a case fatality rate of 1/10,000 in developed countries and 10/10,000 in developing countries. He noted that “despite the data, many will have divergent opinions. Our challenge is to present

our data clearly and openly and to protect our patients and their families.”

### 1.4.5 Etiology of Autism Spectrum Disorder

Dr. Mohammed Uddin provided an overview of the heterogeneity of ASD. He explained that individuals with ASD variably present with structural and functional brain abnormalities,

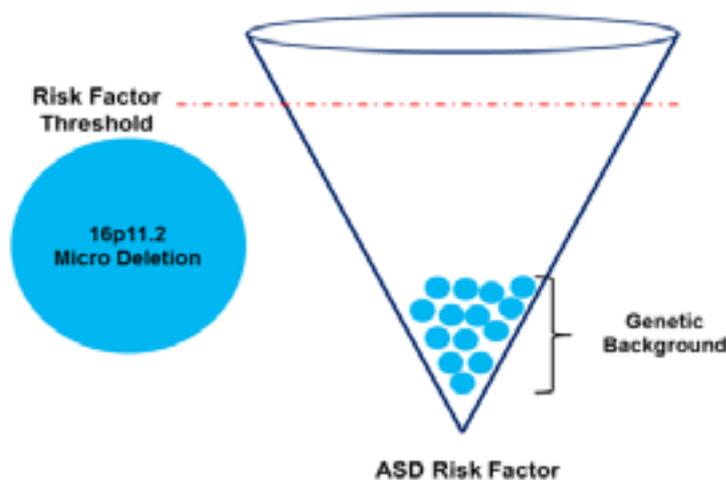
(microcephaly, epilepsy, focal cortical dysplasia, and heterotopia), and functional deficits at the synapse level of the brain (learning disability, ADHD, non-syndromic ID, and OCD).

#### 1.4.5.6 Genomics of Autism Spectrum Disorder

Etiologically, ASD is a multifactorial condition that is the product of the interaction of genetic factors and prenatal, perinatal, and postnatal environmental factors. According to Uddin, non-genetic factors (environmental or others yet unknown) account for 10%-30% of the etiology and genetic factors account for 70%-90% of the etiology. Twin studies give some

insight into the role of genetic factors in ASD etiology. This knowledge will expand as whole genome sequencing technology advances, bringing the ability to profile all mutations. The etiology of ASD is determined by complex genetic factors spanning different forms of genetic variation (or architecture), he explained. For example, a *de novo* mutation (as opposed to an inherited mutation) arises in the offspring and but is absent in the parents. These mutations generally arise in the germ cells of the parent that are transmitted into the zygote. In the case of ASD, the mutation risk factor (16p11.2 microdeletion) is high (Figure 7):

**Figure 7. De novo mutation and ASD**



Source: Uddin presentation at the “Systems of Care for Autism Spectrum Disorder: A Global Perspective” conference hosted by Al Jalila Children’s Specialty Hospital in Dubai, in collaboration with the HMS Center for Global Health Delivery-Dubai, April 1, 2017

Current consensus recommends a genetic test as the first-tier test for individuals with developmental disabilities and congenital abnormalities, according to Uddin. He reported that the total genetic diagnostic yield of ASD currently ranges from 38%-59%.

This yield is similar to that of broader neurodevelopmental disorders. Uddin explained that whole genome sequencing of 5,205 samples from families with ASD,

including 2,067 males and 559 females with ASD (the rest are parents and unaffected siblings), revealed informative mutations of clinical relevance. There was an average of 73.8 *de novo* single nucleotide variants and ~1 exonic *de novo* mutation per subject with ASD, as well as 12.6 *de novo* insertion/deletions (indels) or copy number variations (CNVs) per subject with ASD. Paternal age is significantly and directly associated with number of *de novo* mutations. He explained

that the germ cells, particularly sperm, pass through multiple toxic environments, which can cause mutations during replication and division. 'Critical-exons' enriched with *de novo* mutations were found in children with ASD but not in unaffected siblings. Uddin noted that ASD genes with *de novo* mutations show enrichment of critical-exons that are highly active in prefrontal cortex during prenatal development. These enriched critical-exons are associated with pathways related to the development of neurons.

#### **1.4.5.7 Correlation between autism spectrum morphological severity and mutations**

To examine autism severity and the *de novo* mutational landscape, Uddin reported that they have designed a cohort of 258 consecutively ascertained unrelated children with ASD and have screened the whole genome mutation profile of each family member. As a measure of severity, each case underwent detailed assessments to define morphology scores based on the presence of major congenital abnormalities and minor physical anomalies. They determined that severity is positively correlated with genetic mutations, with high severity associated with a high number of penetrating genetic mutations.

#### **1.4.5.8 Other types of mutations related to ASD**

Uddin reported that there are patches of disorganization in the neocortices of children with autism, citing the case study of a boy with epilepsy and ASD who underwent brain resection. MRI imaging showed evidence of focal cortical dysplasia type 1 in the left anterior temporal cortex, leading to the identification of a *de novo* 4.9Kb heterozygous deletion affecting exon 3-4 of the STXBP1 gene. The boy underwent left anterior temporal resective surgery and achieved complete seizure remission. Analysis showed somatic mosaic mutation in dysmorphic tissue featuring clusters of neurons (rather even distribution). As a result, the investigators reanalyzed the whole genome sequencing

data to identify such somatic mutations. In the whole genome cohort, around 5% of ASD samples carried a somatic mutation that affects 15-35% of blood cells. Uddin explained that these types of high-level somatic mutations arise early in development and may present in the brain.

Uddin commented that pathogenic mutation detection is improving, but therapeutics are lagging behind due to ASD's complex cellular and phenotypic heterogeneity. Future efforts will require better understanding at the level of molecular etiology. For example, 0.5% of all neurodevelopmental disorder cases carry a deletion called 15q13.3 Micro-Deletion Syndrome. Out of 198 cases, developmental disability/intellectual disability was present in 57.7% (epilepsy/seizures, 28.0%; speech problems, 15.9%; ASD, 11%). Ten genes were impacted by the deletion. Therapeutic targets and interventions in development include genetic-diagnosis targeted therapies with gene-specific medications, as well as genome engineering and editing technology (e.g., CRISPR technology).

## **1.5 SYSTEMS OF CARE**

Myron L. Belfer defined systems of care as comprehensive and easily accessible sets of services allowing patients to move from one service to another with minimal obstacles, such as the sharing of medical records or transportation to care. The services within a system offer care with a similar philosophy and are focused on positive outcomes for the patient and/or family. In the context of ASD, systems are not limited to medical care, but also embrace social, educational, and economic services and access to advocacy where needed.

A key consideration in thinking about system of care is whether they should focus on a single disorder or encompass a range of conditions. Single disorder systems may distort the healthcare system and draw resources from the system as a whole. On the other hand, it is easier to advocate and attract funding for single

disorder systems. Establishing and maintaining a primary care-based system of care is now the focus of many initiatives. In order to care for persons with ASD, primary care-based systems of care must provide care for psychiatric co-morbidities and epilepsy. It is also important to avoid medicalization, especially for conditions like ASD that require a multi-disciplinary approach. Belfer suggested that culture could be a barrier to developing a system of care if cultural beliefs inhibit a person from acknowledging the need for, and then receiving, the care they need (for example, a belief that the affected person is in “possession” might prevent a person from receiving appropriate medication to prevent seizures).

Developing a system of care requires effort on multiple fronts. It requires advocacy from the ASD community, including patients and their families whenever possible. Influential advocates with access to financial and/or political resources greatly facilitate system development. Furthermore, a system cannot be established without an adequate number of trained personnel. This has led to training initiatives to develop the skill sets of non-medical personnel to address problems such as ASD. The need for a system of care may be seen as the result of a crisis, or promoted by a grant initiative, but both may lack sustainability without stakeholder support and stable funding. Further, a balance must be struck between “top down” planning and “ground up” planning with the latter fostering stakeholder involvement and cultural relevance.

### **1.5.1 Advantages of systems of care model**

Belfer recounted numerous advantages of the systems of care model. First, systems of care consolidate and coordinate resources to provide efficient care and reduce barriers to access. Coordinated systems prevent frustration on the part of caregivers and providers by streamlining the referral processes. While they may be resource intensive, systems of care are frequently cost

effective. Finally, systems of care provide marginalized individuals with a compassionate and comprehensive care environment where they feel welcome. Within the “medical home” model, the pediatrician (or proxy) acts as orchestra leader to deliver coordinated, accessible, continuous, culturally competent care, as well as providing screening, education, referrals, and follow-up. While it can be difficult to find someone willing to take on this degree of responsibility, having centralized responsibility helps to ensure the provision of coordinated, comprehensive care. He cited some examples of systems of care, including the Kenyan Autism Program and the World Health Organization mhGAP program.

### **1.5.2 Challenges in systems of care model**

Belfer outlined a number of challenges that arise in the systems of care model. When developing and implementing a system of care, it is critical, yet very difficult, for stakeholders to reach consensus on the many aspects of the system, including philosophy, sharing of costs and “profits”, and information sharing. Stakeholders can be influenced by inter-sectoral competition for money and recognition, and distributing resources fairly can be a challenge. Stakeholders and system leaders must be open to critical evaluation, because systems of care must be continually re-assessed for performance and quality control. Furthermore, a strong governance structure with a strong accountability mechanism must be put in place.

One major pitfall of the systems of care model for pediatric patients with ASD lies in the transition from pediatric to adult care. As individuals with ASD progress from childhood/adolescence into adulthood, they may lose membership in their pediatric system of care. In this fragile time of transition, persons with ASD may not be able to find an adult system of care to transfer into or they may be forced into institutional care. Systems must consider mechanisms to catch these individuals who “age out” of systems of care for younger individuals.

Belfer underscored the importance of accurate screening and diagnosis, emphasizing the distinction that screening is not diagnosis. In many cases, critical diagnostic services are lacking, and channeling patients through a system of care with the wrong or inappropriate diagnosis can be very harmful. Furthermore, Belfer cautioned that if a system of care is developed around a single intervention (such as ABA for ASD); it may be detrimental for people who are not particularly responsive to that intervention. Treating the whole patient and maintaining an open mind to potential solutions, rather than adhering to established orthodoxy, is a critical underpinning of successful systems of care. Belfer also cautioned that teams should avoid hospital-based care except in crises, such as acute co-morbid psychiatric or medical crises. Healthcare should not be centered on emergency care, which may lead to hospital dependency.

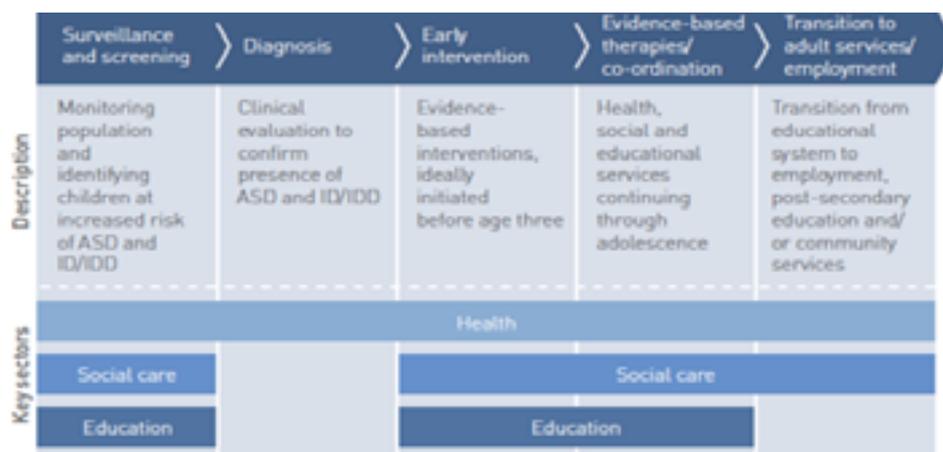
Finally, systems of care are resource intensive. They require both public and private financing

to support ancillary yet essential services, such as social work and education. While there is funding for most programs, competition for funding often exists between sectors, such as education and health.

### 1.5.3 Systems of care for Autism Spectrum Disorder

Leventhal suggested that a system of care for ASD should include the following components: awareness, screening, gold-standard diagnostic evaluation, treatment planning, evidence-based treatment, treatment outcome evaluation, *a priori* outcome measure, and public policy development. Munir called for systems of care to work together to address ASD needs with resources and expertise spanning the health, educational, and social sectors. He offered the following schematic representing the ideal journey of a patient with ASD through the system of care (Figure 8):

**Figure 8. Autism journey**



Source: Munir presentation at the “Systems of Care for Autism Spectrum Disorder: A Global Perspective” conference hosted by Al Jalila Children’s Specialty Hospital in Dubai, in collaboration with the HMS Center for Global Health Delivery-Dubai, March 30, 2017

Albanna emphasized the importance of examining ASD from a “system of care”

perspective. A critical challenge in caring for individuals with ASD is the fragmentation of

services, both within healthcare systems and across related systems, such as education and social services. Poor communication between agencies and lack of clear referral pathways pose barriers and cause delays for patients and their families in accessing care and receiving appropriate assessment and evidence-based treatments. Consequences of service fragmentation include poor health outcomes and emotional burdens on children and their families. Even when services are available, the disjointed referral process can impose barriers to accessing care and inflict substantial financial burdens on individuals and societies.

As an instructive example, Albanna provided an overview of ASD services in Dubai. Albanna explained that Dubai is one of seven Middle-Eastern Emirates that united in 1971 to form the United Arab Emirates. The country has witnessed remarkable advancements in a variety of domains, including the healthcare sector, over the past three decades. Originally founded as a fishing village in the 1580s, Dubai began to transform into a cosmopolitan metropolis in the 1980s. The city's population has tripled since the year 2000. Albanna explained that Dubai is progressing quickly and systematically, and healthcare services are no exception. Healthcare services in Dubai are part of a complex system that includes three main regulatory bodies. Dubai Health Authority (DHA) is responsible for care delivery in public primary, secondary, and tertiary facilities in Dubai, in addition to regulating public and private sector in Dubai. The Ministry of Health (MOH) is responsible for some hospitals, while Dubai Healthcare City Authority (DHCA) is responsible of overseeing and regulating facilities located in Dubai's medical freezone, Dubai Healthcare City (DHCC). Al Jalila hospital is a newly established tertiary care hospital in DHCC, serves as the reference pediatric hospital in the UAE and includes a center of excellence for child and adolescent mental health. As a reference center, Al Jalila Children's is well placed to collaborate with stakeholders to develop systems moving forward, not only in

the realm of healthcare, but also education [Knowledge and Human Development Authority (KHDA) and Ministry of Education] and in social services [Community Development Authority (CDA) and Ministry of Social Affairs, which include therapists and speech pathologists].

Al Jalila Hospital is currently working with the Dubai Executive Council on developing clinical guidelines for children and adolescents with ASD in Dubai. According to Albanna, they are seeking to establish a system for screening and early identification, assessment, intervention, and educational and social inclusion.

In March 2017, a moderated focus group of 43 parents of children with ASD revealed major challenges faced by the parents interacting with Autism services in the UAE. False reassurance is a major concern. When parents consult pediatricians about symptomatic behaviors and delays in their children, healthcare providers often reassure the parents that such delays reflect normal development for infants up to three years of age and seem reluctant to diagnose ASD or other developmental disorders. Health professionals are also reluctant to diagnose children less than five years of age with autism, even when the early signs are present. False reassurance poses a serious barrier to early identification. Additionally, there is no clear pathway for evaluation and treatment. The parents are unclear on which medical specialty to consult for diagnosis and often must make multiple visits to different health professionals to get answers. Sometimes, they do not get answers. Assessments are very expensive and are rarely covered by insurance companies. There are frequently long waitlists, causing the diagnostic process to take up to a year. Furthermore, parents often feel frustrated and confused by the system, and the system of care fails to provide adequate emotional support throughout the process.

Albanna explained that therapies for ASD are overall quite expensive and usually not covered through insurance programs. Many

treatment centers are managed by non-profit organizations. Parents in the focus group reported that treatment centers often administer treatments that are inefficient and of variable quality. Many parents at the focus group reported that they have engaged with unqualified and untrained professionals when accessing treatments and interventions. They also described a lack of transparency about the type of treatments their child is receiving. Arabic speaking parents at the focus group reported that finding Arabic-speaking specialists presents an added challenge. Often, they described being unable to find Arabic-speaking speech therapists, particularly ones with the appropriate dialect. As a result, therapists may conduct sessions in English, even though the spoken language in the home and the parents' preference is to speak Arabic. Despite new government policies to promote inclusivity, parents reported that many schools in Dubai do not want to accept children with autism because these students require extra time, resources, and effort.

## 1.6 A GLOBAL FRAMEWORK FOR ACTION

Munir presented findings of a report completed for the World Innovation Summit in Health (WISH) Autism Forum in November 2016.<sup>12,13</sup> The report had three aims: to identify current challenges faced by communities worldwide in meeting the needs of individuals with ASD; to offer policy recommendations to support these individuals and their families; and, to contribute to building a global

framework for smarter allocation of public resources. The methodology used was semi-structured interviews with samples of ASD-related clinicians, researchers, policymakers, and non-profit workers from twelve different LMICs to gather information about the current level of services provided in their setting and the barriers faced in expanding these services. Interviews helped generate strategies for overcoming these barriers and case examples of successful programs. Munir shared five main goals that emerged from the interviews related to meeting the growing needs of individuals with ASD worldwide:

- Increase awareness and early rates of diagnosis
- Provide evidence-based therapies and delivery of services
- Implement family support systems
- Support access to public education, vocational training and assisted employment
- Participate in high-quality research and surveillance

### 1.6.1 Increasing awareness and rates of early diagnosis

Munir explained that rates of early identification and diagnosis are currently low. According to CDC data from the US,<sup>14</sup> most (39.9%) children are diagnosed at  $\geq 6$  years of age.<sup>15</sup> ASD identification rates vary based on country income and education (Figure 9):

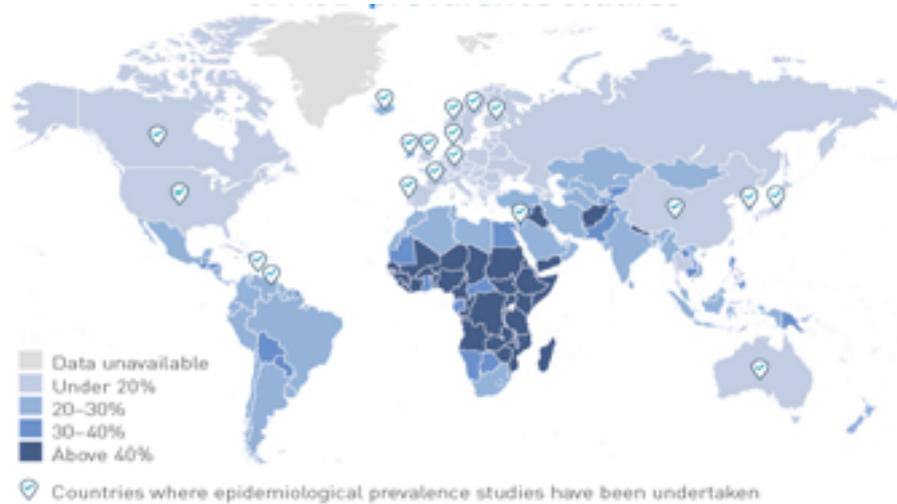
12 A program of the Qatar Foundation for Education, Science and Community Development chaired by Her Highness Sheikha Moza bint Nasser.

13 Munir KM, et al. *World Innovation Summit for Health 2016*

14 Centers for Disease Control/National Center for Health Statistics, *Survey of Pathways to Diagnosis and Services*, 2011

15 Aged 5 years (11.5%), aged 4 years (13.0%), aged 3 years (17.0%), aged 2 years or younger (18.7%).

**Figure 9. Percentage of population under age 15 by country and locations of ASD prevalence studies**



Source: Munir presentation at the “Systems of Care for Autism Spectrum Disorder: A Global Perspective” conference hosted by Al Jalila Children’s Specialty Hospital in Dubai, in collaboration with the HMS Center for Global Health Delivery-Dubai, March 30, 2017

Munir reported that key challenges in early identification and diagnosis include limited knowledge among parents, primary care clinicians, and educators; shortage of clinicians to perform screenings and evaluations; lack of standardized assessment tools in Low and Middle-Income Countries (LMICs); and cultural stigma. Furthermore, many funding agencies are reluctant to support screening due to a lack of resources for follow-up and referral as well as availability of interventions that meet an established standard-of-care. Munir highlighted a set of activities that could promote early identification and diagnosis: increasing awareness among parents and families, educating teachers, and developing simplified diagnostic tools. He also suggested training primary care clinicians in the identification of ASD and providing further training in screening and evaluation to specialized clinicians.

### 1.6.2 Deliver evidence-based therapies and services

Munir explored the challenges in the delivery of evidence-based therapies and services. First, he noted that while there is not a shortage of clinicians available to provide these services, there is an uneven distribution and variable quality of services. Some services are only available privately and at prohibitive cost, it can be difficult to provide or access these services in rural and remote regions. However, strategies to improve the availability of evidence-based therapies include: increasing public funding for services; providing training programs for health professional; increasing the number of professionals licensed and certified to provide ASD services; adapting high intensity programs (programs at highest risk and of greatest severity); and training for parents.<sup>16</sup>

### 1.6.3 Implement family support systems

Munir noted a number of challenges that families with a child with special needs may

<sup>16</sup> Munir commended the WHO on officially linking ASD and neurodevelopmental disabilities in a 2013 report. The WHO parent skills training program targets children 2 to 9-years-old with a developmental delay, including ASD, and aims to promote children’s engagement, communication and adaptive behaviors through play and home routines.

encounter, particularly families living in resource poor settings. These families may feel isolated, stigmatized, and powerless in their efforts to help their child. They may have difficulty finding opportunities for employment, which influences their financial situation. The lack of availability or continuity of ASD services further challenges their ability to support their children. Furthermore, they often lack connections to other families with children with ASD who may be able to provide advice and support. Munir shared some tactics for improving family support systems, such as connecting families online and in person and educating families about their child's disorder and how to access appropriate services. Munir also suggested connecting families with policymakers, such as in the U.S. *Family Voices* program. As an example of a good family support system, Munir described France's Education Thérapeutique du patient (National Plan 1, 2). This approach was developed to address the counterproductive influence of traditional models of mislabeling ASD and blaming parents. The goals of the plan are to decrease parental stress, improve coping skills through education about ASD and treatments, and enhance parental skills in interacting with their children.

#### **1.6.4 Support access to public education, vocational training and assisted employment**

Munir noted that there are many barriers to including children with ASD in public education. In fact, around 20 million children with disabilities are still excluded from public schools worldwide. This is especially a problem in low resource settings and for children with more severe forms of ASD. Teachers may lack the training and resources needed to develop an appropriate curriculum and provide other effective educational modifications. He recommended aiming for educational inclusion rather than merely integration, which is an intermediary step to inclusion.

<sup>17</sup> In India, for example, Action for Autism is training student teachers learn to screen, assess, and teach children with ASD, placing a priority on inclusion training. Stakeholders are included in the development of the training curriculum (medical professionals, teachers, administrators and parents).

#### **1.6.5 Cost-effectiveness of a System of Care for ASD**

Munir reported that the lifetime cost of caring for a person with ASD is approximately \$2.2 million (\$1.4 million for those without comorbid conditions). Direct medical, non-medical and productivity costs relating to ASD amounted to \$268 billion USD in 2015. This number is expected to rise to \$465 billion USD in 2025. When unrecognized and untreated, caring for a person with ASD can incur higher hidden costs on par with estimates for diabetes and exceeding estimates for stroke and hypertension. What set ASD apart from other non-communicable diseases, he noted, are the significantly higher non-medical costs associated with ASD beyond the direct medical costs. As increasing numbers of children with ASD age to adulthood, the costs is likely to further increase.

Munir suggested a set of cost-saving measures, including more inclusive public education in conjunction with community-based support and service delivery. Within public education and employment, further opportunities include training special and general education teachers to care for individuals living with ASD, developing learning resources that are adaptable to individual schools and students, strengthening school infrastructure to enable school systems to collect and report data on children's progress, and improving collaboration between the education, health, and social service sectors.<sup>17</sup>

#### **1.6.6 Participate in high-quality research and surveillance across the life-span**

The fifth theme Munir presented was the need for more high-quality research and surveillance with appropriate levels of rigor and transparency. Munir reported that very little research in ASD has been conducted in LMICs, including epidemiological research and prevalence studies, studies of cost of illness, and research on the effectiveness of

ASD interventions. Barriers to carrying out ASD research in LMICs include lack of national research agendas, poor linkage between research and policy, and insufficient research capacity and networks in LMICs and between HICs and LMICs. Munir advised that training of researchers is essential for the scale up of effective research. Opportunities are available for regional, national, and global coordination and partnerships, often facilitated through academia, governments, and NGOs. To assist with long-term data surveillance, Munir recommended building in evaluations of costs, adaptability, and efficacy with the scale-up of evidence-based interventions.

### 1.6.7 Policy recommendations

Munir shared three policy recommendations:

- Creation of an inter-sectorial coordinating commission to address ASD nationally
- Establishment of interdisciplinary training and research centers for excellence in ASD
- Establishment of a global partnership framework to address significant gaps in

the care of individuals with ASD and NDDs across their lifespans as well as setting research priorities and a research capacity development agenda

Creating an inter-agency coordinating commission to address ASD nationally will involve members from health, education, and social service sectors. A main priority in creating such a commission is to develop and update national strategic plans for ASD that foster independence, inclusion, and productivity for community members with ASD. Creating this partnership will require providing education at the undergraduate, graduate, and post-graduate levels, conducting research and disseminating findings, engaging with policymakers, supporting advocacy efforts, and providing technical assistance on ASD/IDD. Frequent collaboration of regional stakeholders will be vital in setting research priorities, piloting and scaling up interventions, establishing minimum, evidence-based standards of care, and transitioning to national investment rather than direct aid.<sup>18</sup>

<sup>18</sup> Munir highlighted the need for more national commitment and direct investment in health generally rather than overreliance on foreign direct aid, because investments in health provide the greatest dividends for any country (i.e., US\$1 investment yields ~US\$9 of benefits).

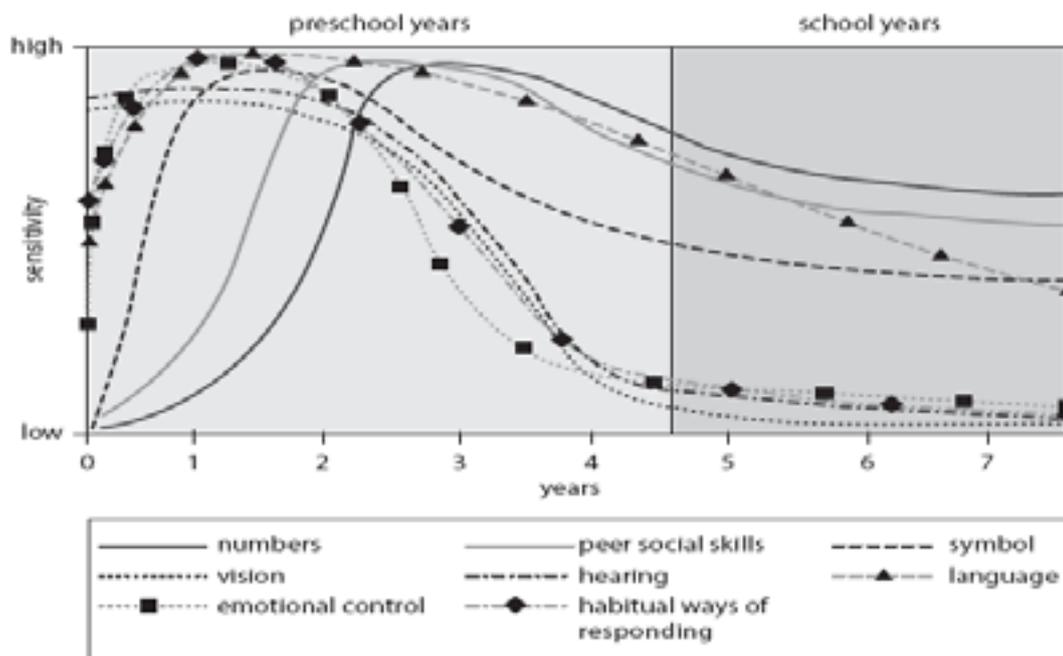
## 2 Identification, Screening, and Early Detection for Autistic Spectrum Disorder

### 2.1 EARLY DETECTION FOR EARLY INTERVENTION

Multiple participants emphasized the importance of identifying and treating children with ASD as early as possible in order to achieve the best possible outcomes. To explicate why this is the case, Eapen provided an overview of a child's developmental trajectory. There is significant and rapid brain growth from birth to 5 years of age. The rate of synaptic development is rapid early in life, with children's brains having twice as many

synapses as adult brains, but the rate of synaptic development quickly declines with advancing age. Eapen noted that while the biology of the brain is fixed, the brain is altered by experiences. Therefore, the first few years of life are a critical time for neurodevelopment, when increased synaptic activity leads to growth, development, and learning in vital areas such as hearing, behavioral control, language, and social skills (Figure 10):

**Figure 10. Sensitive periods in early brain development**



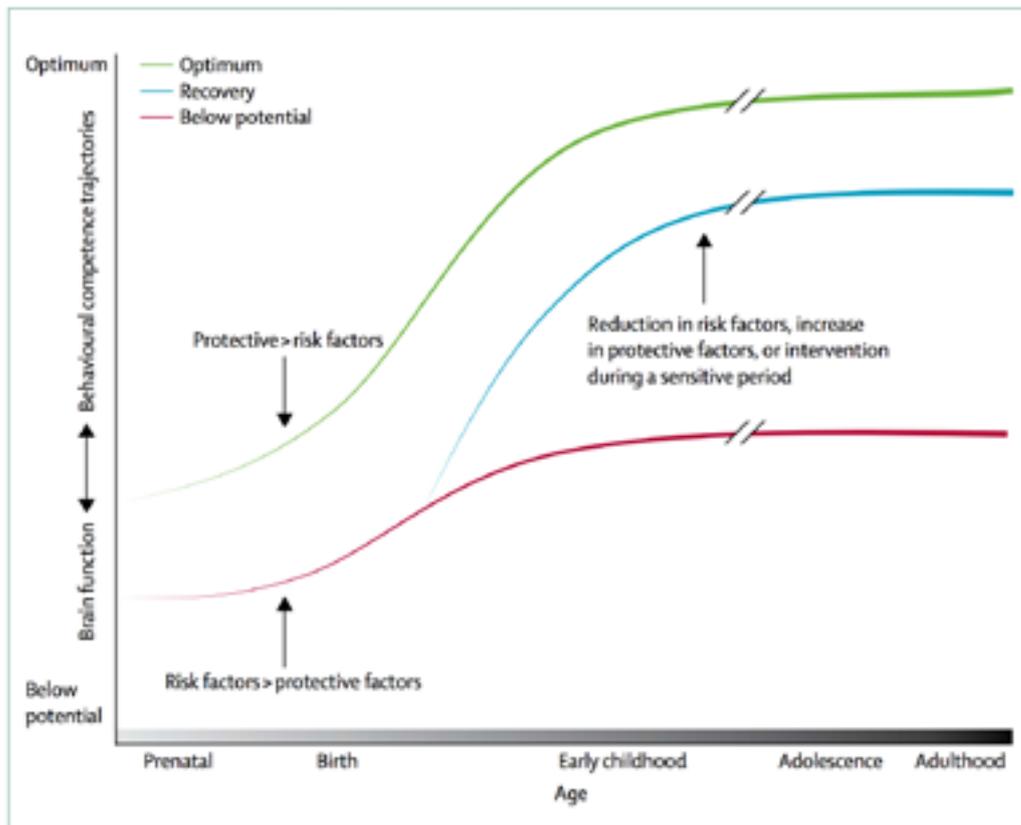
Source: Council for Early Child Development (2010).

Source: Eapen presentation at the "Systems of Care for Autism Spectrum Disorder: A Global Perspective" conference hosted by Al Jalila Children's Specialty Hospital in Dubai, in collaboration with the HMS Center for Global Health Delivery-Dubai, March 30, 2017; Council for Early Child Development, World Bank, 2010

Eapen warned that there is a socioeconomic gradient to risk, with more disadvantaged children facing a higher risk of dysfunctional development. Because experiences affect the brain's circuitry neglect, abuse, and deprivation have been shown to negatively affect brain development; these effects are visible in brain scans of healthy child

compared to children who have endured neglect and abuse. Eapen explained that differing trajectories of brain development are a function of genetics and exposure to risk and protective factors (Figure 11):

**Figure 11. Differing trajectories of brain and behavioral development as a function of exposure to risk and protective factors**



Source: Eapen presentation at the “Systems of Care for Autism Spectrum Disorder: A Global Perspective” conference hosted by Al Jalila Children’s Specialty Hospital in Dubai, in collaboration with the HMS Center for Global Health Delivery-Dubai, March 30, 2017; Walker et al. Lancet 2011

Eapen emphasized that early identification maximizes children’s opportunities to receive early intervention during a period of increased brain plasticity, leading to improved cognitive outcomes and reduced levels of intellectual disability. As the sensitive period for development closes and brain plasticity decreases, it becomes more difficult for a child to ‘catch up’ developmentally and the

physiological effort required to enhance neural connections increases.

## 2.2 OVERVIEW OF SCREENING FOR AUTISM SPECTRUM DISORDER

Screening is the lynchpin of early identification within systems of care for ASD. Leventhal and Eapen provided an overview of some of commonly used ASD screening instruments:

- Social Emotional Growth Scale/Chart (SEGC)<sup>19</sup>
- Modified Checklist for Autism in Toddlers (M-CHAT)<sup>20</sup>
- Autism Spectrum Screening Questionnaire (ASSQ)<sup>21</sup>
- Social Communication Questionnaire (SCQ)<sup>22</sup>
- Ages and States Questionnaire (ASQ-3)<sup>23</sup>
- Brief-Infant-Toddler Social-Emotional Assessment (BITSEA)<sup>24</sup>
- CSB-DP Toddler Checklist<sup>25</sup>
- Parent Evaluation of Developmental Status<sup>26</sup>
- Gilliam Autism Rating Scale (GARS-2)<sup>27</sup>
- Childhood Autism Rating Scale (CARS2)<sup>28</sup>
- M-CHAT Follow-up Interview (MCHAT-FI) M-CHAT Follow-up Interview (MCHAT-FI); CHAT-23; Q-CHAT (10 most sensitive items of MCHAT)

Screening instruments are often combined, noted Leventhal, because no single instrument is perfect. Screening can be challenging to complete because many of the instruments are very time consuming. Specialized clinicians who are trained to administer the instruments must perform screening.

## 2.2.1 Gold standard instruments for Autism Spectrum Disorder

According to Leventhal, the “gold standard” diagnostic instruments for ASD are the Autism Diagnostic Interview – Revised (ADI-R),<sup>29</sup> the Autism Diagnostic Observation Schedule – two (ADOS-2),<sup>30</sup> and the new Toddler ADOS and Adapted ADOS. With both the ADOS-2 and ADI-R instruments involving components of clinical observation, the patient’s results from these instruments provide ample evidence to make a referral for comprehensive assessment and potential diagnosis. Administered by trained examiners, the ADOS-2 is a tool consisting of an exam that includes structured and unstructured tasks that are sensitive to ASD-related behaviors. The exam is not a cognitive test, but rather it is a tool designed to collect standardized information about social behavior; use of vocalization, speech, and gesture; play and interests; and typical and atypical behaviors. The ADI-R and ADOS-2 combine to be fairly predictive of ASD; Leventhal reported that of 108 children referred for diagnosis of autism at age 2, at 5 years 61% were diagnosed with autism, 25% were diagnosed with PDD-NOS, and 14% were determined to be non-spectrum (language-impaired or intellectual disability).

Leventhal listed many other potentially useful instruments, including questionnaires for caregivers (SCQ<sup>31</sup>; CHAT<sup>32</sup>; Pervasive Developmental Disorders Screening Test [PDD]<sup>33</sup>; E2<sup>34</sup>) and ratings from observation

19 Greenspan *Psychcorps* 2004

20 Robins et al. *J Autism Dev Disord* 2001

21 Ehlers et al. *J Autism Dev Disord* 1999

22 Lord et al.

23 Squires J & Bricker D., 2009

24 Briggs-Gowan et al. *J Pediatr Psychol* 2013

25 Wetherby et al. *Autism* 2008

26 Glascoe *Ellsworth & Vandermeer Press* 2007

27 Gilliam *PRO-ED* 2006

28 Schopler et al. *J Autism Dev Disord* 1980

29 Lord et al. *J Autism Dev Disord* 1994

30 Lord et al. *Western Psychological Services* 2012

31 Lord et al.

32 Baron-Cohen et al. *Br J Psychiatry* 1992

33 Siegel 2004

34 Rimland 1964

(GARS<sup>35</sup>; CARS<sup>36</sup>; BRIAAC<sup>37</sup>). The Social Responsiveness Scale (SRS-2)<sup>38</sup> allows the measurement of social reciprocity in both clinical and general populations through a parent or teacher rating scale. An overall score indicates the severity of social deficits, while subscales measure social awareness, social information processing, and capacity for reciprocal social responses, social anxiety/avoidance, and characteristic autistic preoccupations/traits. The SRS-2 has high test-retest reliability and strong correlations with DSM-IV and DSM-5 ASD criterion scores.

### 2.2.2 Screening versus surveillance for Autism Spectrum Disorders at the population level: a case for proportionate universalism

Eapen explained that screening is a cross-sectional evaluation. In any patient population, there are children with normal development, children with obvious abnormal development, and those in between. Developmental surveillance is a flexible and longitudinal process through which trained healthcare professionals identify “at risk” children who may have developmental problems through clinical observation and validated screening tools over multiple time points. Eapen emphasized that universal developmental surveillance is the critical first step to early intervention: “It is important to identify developmental vulnerability as early as possible through universal developmental surveillance to allow timely referral to early intervention; early intervention at a population and individual level can improve developmental outcomes.”

Eapen reported that pilot data currently under review from a recent study comparing

early and late diagnosis makes a clear case for focusing on early general development.<sup>39</sup> The age at which early intervention began was significantly associated with Full Scale IQ at school age for children diagnosed early ( $r = .46$ ), but not for the group diagnosed later ( $r = .007$ ). Moreover, while the severity of ASD was similar in both groups of school age individuals, 77% of children in the early-diagnosis group attended a mainstream primary school, compared to only 58% of children in the late-diagnosis group.

Eapen reported that another study<sup>40</sup> of a birth cohort of 2000 children in Sydney, Australia showed significantly elevated developmental risks associated with the following adjusted risk factors: male gender, perinatal risk factor identified,<sup>41</sup> mother born overseas, English not being the primary household language, and household socioeconomic disadvantage.<sup>42</sup> Eapen explained that those who are most in need of services - families with highest disadvantage and children with the greatest developmental risk - were less likely to access services, illustrating the “inverse care law”. For example, families above the poverty line were 3.8 times more likely to attend a ‘well baby check’ than families below the poverty line. Mothers with tertiary education were 2.6 times more likely to attend clinics than were mothers with secondary-level or lower education. Additionally, mothers who reported being informed of or remembered the 6-month check were 2.1 times more likely to attend than those who were not informed or could not remember, underscoring the importance of health education and awareness.

The ramifications of the “inverse care law” – the mismatch of the availability of

35 Gilliam 1995

36 Schopler et al. 1988

37 Rutter et al. 1978

38 Constantino & Gruber, 2012

39 Clark et al. *J Autism Dev Disord*. 2018

40 The Watch Me Grow study – CORRECT CITATION??

Woolfenden et al. *BMC Pediatr* 2016

41 Defined as low birth weight/preterm gestation and/or admission to special care nursery or neonatal ICU.

42 Defined as income <25,000 and/or father unemployed and/or mother didn't complete high school; low SEIFA.

services with the needs of the populations served – have significant implications for policy development and service delivery, Eapen maintained. Thus, children with multiple risk factors are more vulnerable to developmental delays, yet less likely to access health promotion programs. To minimize barriers to accessing services, the services must be delivered within a framework of ‘proportionate universalism’ in which free universal health services are provided to all children and families, with additional support available commensurate with additional needs.<sup>43</sup> Therefore, universal developmental surveillance needs to be a combination of a universal and a targeted approach.

To address the cumulative risks that children born at a disadvantage face throughout their development and beyond requires a longitudinal approach to service provision, with a particularly intensive approach during early development when the brain’s plasticity is at a maximum. Each stage of integrated service delivery must build on to the next – “a form of ‘cumulative buffering’ for cumulative risks.” The inequity<sup>44</sup> of compounded disadvantage—environmental, developmental, emotional, and so on—is significant, but Eapen explained that biology is not destiny. Brain development is guided by activity-dependent synapse formation and circuitry development, which is a bidirectional interface that allows for modification by genetics and the environment. Eapen reiterated that early intervention in the preschool years could enhance social-emotional and social-cognitive development and lead to improved outcomes.

## 2.3 ASSESSING AUTISM SPECTRUM DISORDERS: GLOBAL AND REGIONAL EXPERIENCES

### 2.3.1 Universal Developmental Surveillance in New South Wales, Australia

Eapen explained that New South Wales, Australia has a program for universal developmental surveillance of all children from birth to five years of age. Each child receives a “Blue Book” Personal Health Record (PHR) at birth for parents to maintain health records and results of evaluations, including neonatal testing, immunization records, hearing tests, vision tests, developmental checks, and more. The PHR recommends developmental checks at 6 months, 1 year, 18 months, 2 years, 3 years, and 4 years of age. Anticipatory guidance around child development is also provided by child and family health nurses and general practitioners (GP) using the CDC Learn the Signs: Act Early program and other resources.<sup>45</sup>

ASD surveillance is embedded within the developmental surveillance framework. The framework is both universal and targeted, in that ASD assessments, such as the “Ages and Stages Questionnaire,” are not completed for every child but for those in whom concerns were raised. The *Watch Me Grow* web app (WMG- Electronic platform) was developed to streamline the screening process and minimize time required for screening during routine medical visits. For example, at the 18-month vaccination visit, parents complete a survey on the WMG app regarding their child’s behavior and performance. These surveys contain items from the CDC Learn the Signs Act Early program and QCHAT (10 most sensitive items from the MCHAT) and the results of this assessment can flag children at risk for developmental delays. Results of the questionnaires are transmitted through Health

43 She suggested that education for parents needs to begin with conception or pre-conception, and a psychosocial risk assessment should be done for all parents.

44 She drew a distinction between inequality—differences between groups, e.g. such as a higher rate of cerebral palsy in preterm versus term babies—and inequity, which is inequality that is unfair, unjust, systematic, avoidable, and unnecessary, e.g. higher rate of preterm birth in children from lower socioeconomic status populations compared to their higher socioeconomic status peers.

45 CDC 2018

Link to the patient's General Practitioner (GP), allowing the GP time to review the results before discussing with the family. Based on the WMG-E results, further assessments (e.g. Ages and Stages Questionnaire Social and Emotional (ASQ-SE) and MCHAT Follow-up Interview) are carried out and appropriate referrals for ASD diagnostic assessments and early intervention programs are made as needed.

Eapen emphasized that parents need to be educated about the early signs of ASD to

be able to act early. Following the GP visit, parents are provided with guidance on typical child development and normal milestones, as well as age-relevant ideas for promoting healthy development. GPs are also provided with "red flag" referral guidelines (e.g. Central Queensland Hospital and Health Service Red Flags Early Identification Guide for children aged birth to five years, 2<sup>nd</sup> edition 2016)<sup>46</sup>:

Figure 12. Red Flag referral guidelines

Area	6 months	9 months	12 months	18 months	2 years	3 years	4 years	5 years	Red flags at any age
<b>Social/emotional</b>	Does not smile or interact with people	Not sharing enjoyment with others using eye contact or facial expression	Does not notice someone new Does not play safe turn-taking games (e.g. peekaboo, rolling a ball)	Lacks interest in playing and interacting with others	When playing with toys tends to bang, drop or throw them rather than use them for their purpose (e.g. tiddly dolls, build blocks)	No interest in pretend play or interacting with other children Difficulty noticing and understanding feelings in themselves and others (e.g. happy, sad)	Overreacting or unable to play cooperatively	Play is different than their friends	Strong parental concerns Significant loss of skills Lack of response to social or verbal stimuli
<b>Communication</b>	Not starting to babble (e.g. early, early)	Not using gestures (e.g. pointing, showing, waving) Not using two part babble (e.g. babba, dada)	No babbling phrases that sound like talking No response to familiar words (e.g. bottle, dada)	No clear words Not able to understand short requests (e.g. "Where is the ball?")	Not learning new words Not putting words together (e.g. "push-er")	Speech difficult for familiar people to understand Not using simple sentences (e.g. "Big car?")	Speech difficult to understand Not able to follow directions with two steps (e.g. "Put your bag away and then go play")	Difficulty writing a parent/whisper Not able to answer questions in a simple conversation (e.g. "What's your name? Who is your family? What do you like to watch on TV?")	Poor interaction with adults or other children Lack of, or limited eye contact Differences between right and left sides of body in strength, movement or tone
<b>Cognition, fine motor and self-care</b>	Not reaching for and holding (spreading) toys Hands frequently clenched Does not explore objects with hands, eyes and mouth Does not bring hands together at midline	Does not hold objects Does not "give" objects on request Cannot move toy from one hand to another	Does not feed self (finger foods or hold-own bottle) cup Unable to pick up small items using index finger and thumb	Does not scribble with a crayon Does not attempt to stack blocks after demonstration	Does not attempt to feed self using a spoon and/or help with dressing	Does not attempt to dress self (such as fastening or shoelaces) Difficulty in manipulating small objects (e.g. threading beads)	Not toilet trained by day Not able to draw lines and circles	Concerns from teacher about school readiness Not able to independently complete everyday routines such as feeding and dressing Not able to draw simple pictures (e.g. stick person)	Marked low tone (floppy or high tone stiff) and significantly impacting on development and functional motor skills
<b>Gross motor</b>	Not holding head and shoulders up with good control when lying on tummy Not holding head with control in supported sitting	Not rolling Not sitting independently without support Not crawling (e.g. creeping, crawling)	No form of independent mobility (e.g. crawling, commandeering, bottom shuffling) Not pulling to stand independently and leaning on for support	Not standing independently Not attempting to walk without support	Not able to walk independently Not able to walk up and down stairs holding on	Not able to walk up and down stairs independently Not able to run or jump	Not able to walk, run, climb, jump and use stairs confidently Not able to catch, throw or kick a ball	Not able to walk, run, climb, jump and use stairs confidently Not able to hop five times on one leg and stand on one leg for five seconds	

Source: Central Queensland Hospital and Health Service Red Flags Early Identification Guide, Child Development Program with Brisbane North Primary Care Network 2016

Surveillance is more than once-off screening, Eapen explained. The PHR developmental checks are repeated every 6 months until the child is 4 years of age. If concerns are raised,

further developmental assessments are performed and the child is referred to an allied health specialist (e.g., speech, occupational therapy, audiology, etc.) as appropriate. ASD

46 Child Development Program with Brisbane North Primary Care Network 2016

tools are used if concerns are primarily in the social and communication domains.

## **2.4 IDENTIFICATION AND SCREENING IN ASD SYSTEMS OF CARE: KEY ENABLERS AND SUCCESS FACTORS**

During the small group-planning workshop, expert participants discussed key factors integral to the success of identification and screening within systems of care for ASD. Dr. Sandra Willis<sup>47</sup> set the stage by outlining the pathway of early identification, referral, and diagnosis that will serve as the basis of the new Dubai system of care for autism. The plan involves promoting awareness of ASD among families and the community, with a particular focus on new parents and high-risk parents. Potential strategies include developing an evidence-based targeted awareness campaign, creating an ASD information pack for the media, and facilitating online bilingual resources on autism. According to Willis, the Dubai system of care plans to develop developmental and autism screening programs for children aged 0-5 years in health settings, including child health and wellness clinics in primary care centers, pediatric clinics, early intervention centers, early childhood learning centers, and children's homes (in conjunction with family support). ASD screening in children will become routine in pediatric/child health clinics and hospitals by linking up with the immunization process. Trained and licensed nurses will serve as facilitators for referrals. Screening for older children (aged 6 years and up) will be carried out in homes and schools as well as early intervention and rehabilitation centers. A case manager for a full diagnostic assessment (described in Chapter 3) refers children identified via screening.

Willis emphasized that inter-agency collaboration across social, health, and education sectors is a "must" for a successful system of care. Multiple participants

highlighted the importance of a family-centered process that empowers families with guidance on where and how to access providers and services and what to do if they have concerns about a child. Participants also suggested mapping existing services to highlight providers of high-quality ASD services and weed out lower quality providers and practices. Starter packages containing basic information about services and providers, clear referral pathways, information about navigating the system, and legal rights can be disseminated to families through schools, providers, and primary health care settings. An online portal or directory could serve as a single point of contact and provide resources to parents and caregivers in the multiple languages.

Participants noted the importance of ensuring that child health services have multiple points for early identification, with validated, regulated, and recurrent assessment programs operating in clinical settings, the home, mainstream childcare, and schools.<sup>48</sup> The ASD care pathway can start in the primary care setting (in both the public and private sectors) for pediatric health, where providers can initiate the process of further assessment for developmental issues in children as young as 9 months of age. Validation of health records through use of the Child Health Record book can ensure that children are assessed for developmental progress. Another strategy to aid in early identification is to create an approved information pack and training program for school-based learning support units and early childhood learning health clinics to assist educators in identifying red flags and early signs of ASD and developmental delays. Participants discussed potential challenges related to implementing a home visit program, possibly at one month of age, to bridge the gap between providers' and parents' perspectives on the "Child Health Record book". Home visits are expensive and complicated, but they circumvent the chaos of a pediatrician's office and offer the benefits

47 Sandra Willis, PhD, Advisor, Social Development Policy and Strategy, Social Development Department, The General Secretariat of the Executive Council of Dubai, Dubai, UAE

48 A participant suggested the potential role of religious leaders in providing entry into the system.

of facilitating screening, detection of maternal depression, and domestic violence.

Willis commented that engendering high-level and inter-agency political will is critical for establishing core values for systems of care. Participants recommended that public and private stakeholders be present and involved in the establishment of ASD systems of care. Families are often eager to help and can play a vital role in advocacy, identifying gaps in ASD care, and promoting awareness. One participant noted that community acceptance of a child with ASD and his or her family is very important to their ability to thrive. The media can play a key role in disseminating information about ASD and pathways of care that are communicated in 'layman's terms' to the general public as well as promoting awareness and mitigating stigma.

Participants further explored prenatal and newborn screening within systems of care for ASD. Prenatal screening can ascertain one's risk of ASD related to family history, exposure to toxins, parental age, and consanguinity. Participants recommended setting a non-negotiable minimum standard of basic neonatal testing across public and private health settings. Excluding people from these tests is a human rights violation, thus basic neonatal testing should be part of the essential benefits package for universal health coverage. Testing could include metabolic tests, thyroid function, sensory screening, and hearing tests, and these results can be logged into a Child Health Record book for later reference and longitudinal assessment. The results of such testing can lead to rapid identification and enrollment in services that can maximize a child's chance of normal development. For example, hearing tests can identify hearing problems at birth, allowing prompt intervention to prevent hearing problems from contributing to future language delay in a child and prevent misdiagnosis of autism. Early detection for toddlers up to the age of three years should focus on

milestones of language and behavior (as well as behavioral changes).

Participants reiterated that the screening system should span child health clinics in the public health sector, pediatric clinics in the private sector, early learning centers, and inside the home. Important elements of ASD systems of care include:

- Screening sites
- Screening content
- Ages of screening
- Accessibility
- Coordination between sites and services
- Quality assurance
- Acceptability of the screening paradigm
- Repetition: screening multiple times
- Dissemination of information
- Multiple observers in primary health clinics and early childhood learning centers
- Ensuring privacy, especially in communities where developmental issues are stigmatized

Participants discussed the concept of "hot-spotting," a strategy in which resources and attention are focused on those who face the highest need.<sup>49</sup> Additionally, families exhibit better healthcare outcomes when they are strongly connected at the primary care level<sup>50</sup>. One strategy to promote involvement in the primary care structure is to require the registration of children with primary care providers, who will serve as their main provider and coordinator of care. Another strategy is to establish centers in the community (e.g., in public parks) where services can be linked, not only for ASD but also for a full spectrum of integrated care services.

49 Gawande *The New Yorker* 2011

50 Cooley, W. C., McAllister, J. W., Sherrieb, K., & Kuhlthau, K. (2009). Improved outcomes associated with medical home implementation in pediatric primary care. *Pediatrics*, 124(1), 358-364.

### 3 Diagnosis and Comprehensive Assessment of Autistic Spectrum Disorders

Screening for ASD is only the first step in diagnosing ASD. Making a definitive and differential diagnosis requires comprehensive and multidisciplinary follow-up assessments after the initial screening. Comprehensive and multidisciplinary clinical assessment, according to Leventhal, is used to understand the patient’s clinical condition and possible co-morbidities (medical and psychiatric) and subsequently develop a treatment and longitudinal monitoring plan.

Eapen conceptualized ASD as a triad of impairments: people with autism exhibit impaired communication skills, impaired social interaction skills, and repetitive and restricted behaviors. The DSM-5 combined the deficits in social interaction and communication into a single “social communication” domain, which along with restricted repetitive behaviors are required for a diagnosis of ASD (Figure 13):

**Figure 13. Domains of ASD**



Source: Eapen presentation at the “Systems of Care for Autism Spectrum Disorder: A Global Perspective” conference hosted by Al Jalila Children’s Specialty Hospital in Dubai, in collaboration with the HMS Center for Global Health Delivery-Dubai, March 31, 2017

Leventhal emphasized that diagnosing ASD requires a multimodal, multidisciplinary

assessment process requiring time, energy, and multiple team members, declaring, “It

takes a village to make a diagnosis.” Team members include screeners (primary care, nurses, and educators) and evaluators from the fields of child and adolescent psychiatry; pediatric neurology; developmental and behavioral pediatrics; developmental, neuro-, and educational psychology; speech and language pathology; Board Certified Behavior Analysis (BCBA); genetics; and more. Information is gathered through numerous channels, including:

- Screening
- Clinical interview
- History and mental status exam
- Standard diagnostic instruments [Autism Diagnostic Interview (ADI) and Autism Diagnostic Observation Schedule (ADOS)]
- Psychological testing (cognitive, educational, and other)
- Adaptive function (Vineland Adaptive Behavior Scale, ABC data collection)
- Physical examination, including neurological and sensory exams (to rule out deafness and blindness)
- Laboratory testing (used only if clinically indicated)

Dr. Omar Almodayfer<sup>51</sup> questioned whether a full assessment is always necessary to diagnose, especially if the child is thoroughly assessed before the placement into appropriate intervention and rehabilitation programs. Leventhal explained that it is possible to diagnose without the ADI and ADOS, but a full assessment improves precision in diagnosing ASD, establishes each patient’s baseline condition, and increases the chances of diagnosing comorbidities. In any case, it is critical to set a standard for the community (i.e., the standard of care you would want for your own children) and do everything possible to achieve that standard, acting within the local context. A participant expressed concern about recommending that diagnosis can be made without assessment in the absence of expertise: “this wouldn’t be acceptable in physical health and it shouldn’t be acceptable for mental health.” Gaddour highlighted the current situation of overwhelming prevalence, excessive wait times, and lack of effective interventions. Wait times would extend to years if the full gold standard was imposed, he argued, so pragmatism is required in low-resource settings.

<sup>51</sup> Dr. Omar Almodayfer, Head of Mental Health Department, KAMC- MNGHA and CEO, Human Development Co.

### **Box 1-2: Why make comprehensive diagnostic assessments?**

Leventhal outlined the reasons for conducting diagnostic assessments:

- Establish clinical phenotype
- Estimate prognosis
- Create basis for treatment plan
- Educate patient and family and prepare them for communication with family, community and professionals
- Facilitate inter-professional communication
- Facilitate linkage to social support
- Create affiliations with similar conditions
- Categorize for research participation
- Establish eligibility for services, including insurance
- Complete administrative obligations

A participant wondered about the practical importance of diagnosis. Leventhal countered that a diagnosis of ASD serves multiple needs. It provides parents with a meaningful way to explain behavior their child and his/her behavior and it establishes their eligibility for services. Importantly, it links individuals and families with others who are undergoing similar experiences with ASD. While a diagnosis is often required to access services, it can also encourage the family to pursue those services for their loved one with ASD.

Another participant noted the phenomenon of parents resisting a diagnosis of ASD in their child due to stigma in many parts of the world, and that affluence, rather than a label of ASD, determines who receives services. Leventhal observed that the term “autism” was highly stigmatized when he started working in the US and in Korea. However, increases in publicity and access to services have helped to reduce the stigma around autism and ASD substantially.

Belfer noted that the stigma could affect clinicians as well and discourage them from

working with patients who have childhood mental health disorders. He suggested that ASD should be included in pediatric clinical training so that doctors are more familiar with the disorder and therefore feel more comfortable caring for patients with ASD and spreading awareness about the disorder throughout the community.

Hanan Derby<sup>52</sup> noted that some parents do not seek help early because they normalize or justify their child’s delayed development. Leventhal agreed that this is a common clinical problem. He continued to state that, despite the clinician’s frustration at the late presentation of a child with ASD, it is not helpful to tell parents that they should have come earlier. Rather, a clinician should reassure the parents that they are doing the best they can for their child. Eapen concurred, noting that families have their own reasons for normalizing the behavior, and it is important to take into account a family’s cultural context and provide families with hope, opportunities, and a plan.

<sup>52</sup> Hanan Derby, MBBS, Consultant Child and Adolescent Psychiatrist, Al Jalila Children’s Specialty Hospital, Dubai, UAE

Another participant reported observing clinicians use ADOS to over-diagnose ASD. Leventhal clarified that it is not the instrument that causes over-diagnosis, rather misuse by the clinician administering it. He noted that this phenomenon of over-diagnosis is a problem throughout medicine when a single measure is used to conclusively diagnose individuals. While the ADOS is a useful and precise tool in terms of the clinical data collected, proper diagnosis requires skillful and knowledgeable aggregation of a broad spectrum of clinically-relevant information.<sup>53</sup>

### 3.1 ESSENTIAL ELEMENTS FOR THE DIAGNOSIS OF AUTISM SPECTRUM DISORDERS

Leventhal outlined a set of warning signs for ASD. Leventhal noted that delays in language development are strong predictors of ASD:

- By 6 months: no smile or expression of joy
- By 9 months: no sharing of sounds, smiles, or facial expression
- By 12 months: no babbling, no reciprocal gestures (pointing, showing, reaching, waving)
- By 12 months: no response to own name
- By 16 months: no words
- By 24 months: no meaningful 2-word phrases (not echoing)

Recent research suggests that ASD has an early course. For instance, there is evidence of worsening attention to the eyes from 2 months to 6 months of age,<sup>54</sup> over-arousal in response to eye gaze,<sup>55</sup> and regression. These findings suggest that the primary deficit in ASD is neurobiological, with a secondary deficit of inattention to social information in the eye region of the face.

- Eapen provided an overview of diagnostic tools available (in addition to the

screening tools discussed in the previous chapter):

- Autism Diagnostic Interview-Revised (ADI-R)
- Autism Diagnostic Observation Schedule-Generic (ADOS-G)
- The Developmental Dimensional Diagnostic Interview (3Di)
- Use Diagnostic and Statistical Manual (DSM) Criteria
- Autism Behavior Checklist (ABC)
- Childhood Autism Rating Scales (CARS)

#### 3.1.1 Measures of cognitive and adaptive function

Leventhal explained that measures of cognitive function must include both verbal and non-verbal tests, because using only language-dependent tests may produce inaccurately low scores in individuals with a language disorder. Verbal cognitive measures include the Wechsler (WPPSI, WISC, WAIS) and the Stanford Binet. Non-verbal cognitive measures include the DAS (Differential Abilities Scale), Mullen Scales of Early Learning, and Raven's Progressive Matrices. The Aberrant Behavior Checklist (ABC)<sup>56</sup> can be used with all neurodevelopmental disorders. The ABC is a 58-item standardized checklist comprised of 5 subscales<sup>57</sup> of irritability, lethargy and social withdrawal, stereotypic behavior, hyperactivity/non-compliance, and inappropriate speech. Each of the 58 items is scored 0 to 3 points (0=no problem; 3=severe problem); higher ABC subscale scores correlate with increased symptom severity. Measures of adaptive function include the Vineland Scales of Social Maturity, the Alpern-Boll Developmental Profile, and the Diagnostic Adaptive Behavior Scale (DABS) from the American Association

<sup>53</sup> In Eapen's practice, clinicians prepare diagnoses as a team. Before settling on a diagnosis, each member writes down their thoughts and their level of certainty.

<sup>54</sup> Jones and Klin *Nature* 2013

<sup>55</sup> Dawson et al. *Pediatrics* 2010

<sup>56</sup> Aman et al. *Am J Ment Defic* 1985

<sup>57</sup> The scale is observer-rated and parent-driven, and under the guidance of a clinical specialist.

on Intellectual and Developmental Disability (AAIDD).

### 3.1.2 Language Assessment

Leventhal recommended both expressive and receptive language assessments, ideally performed by a speech and language pathologist, to capture the full spectrum of a child's verbal and non-verbal communication abilities. Expressive and receptive language includes reciprocal language, vocalization (articulation, vocabulary, prosody, and inflection), gesture (hands, face, and body), and written language. Language measures include Clinical Evaluation of Language Fundamentals (CELF), Peabody Picture Vocabulary Test (PPVT), Goldman-Fristoe (articulation), and Test of Pragmatic Language (TOPL).

### 3.1.3 Functional Behavior Analysis (FBA)

Each patient should be assessed using Functional Behavior Analysis (FBA) for behaviors consistent with ASD. The FBA is a structured analysis of problematic behaviors that interfere with learning, adaptation, and participation in the environment. The analysis involves multiple observations conducted at different times and in different environments and situations. Some ASD behaviors may be responsive to medication or other behavioral interventions, said Leventhal. The results of the FBA are used to inform a targeted behavioral intervention plan tailored to each individual.

### 3.1.4 Other Potential Assessments

Other potential assessments described by Leventhal include: psychopathology assessments [such as the Child Behavior Checklist (CBCL) and the Behavior Assessment System for Children (BASC-2)]; testing for seizure disorders; psychoeducational testing; neuropsychological testing; occupational therapy assessment; physical therapy assessment; and sensory assessments (such as vision and hearing tests). Selection of these

tests depends on their variable cost-utility ratios as well as the assessment results and individual characteristics of each patient. Laboratory studies to be considered include genetic testing (for Fragile X, SNP microarray, WES/WGS, and organic acids, for example), imaging in the case of focal neurological findings, Electroencephalography (EEG) in the case of possible epilepsy, polysomnography (PSG) for unremitting sleep problems, and heavy metal testing in the case of suspected exposure. Leventhal mentioned that assessments of immune function, vitamin levels, and enzymes may not be as helpful in developing intervention plans, but they should be considered when clinically relevant.

Eapen explained that children who fail developmental screening should receive further medical evaluation, which may include:

- Evaluation for iron deficiency anemia
- Evaluation for lead poisoning (if risk factors for lead poisoning present)
- Formal hearing testing (BAER)
- Vision testing (full ophthalmologic exam)
- Thyroid function testing (if no NBS, or signs of thyroid disease)
- Metabolic testing
- Genetic screening
- Neuroimaging (as indicated)

### 3.1.5 Diagnostic Criteria for ASD

Eapen recounted the diagnostic criteria for ASD in detail. ASD is characterized by persistent deficits (current or historical) in social communication and social interaction across multiple contexts, as manifested by the following (examples are illustrative, not exhaustive):

- Deficits in social-emotional reciprocity. Deficits can include abnormal social approach, failure of normal back-and-forth conversation, failure to initiate or respond to social interactions, and reduced sharing of interests, emotions, or affect.

- Deficits in nonverbal communicative behaviors used for social interaction. These deficits can include poorly integrated verbal and nonverbal communication, abnormalities in eye contact and body language, misunderstanding the use of gestures, or a total lack or misuse of nonverbal communication.
- Deficits in developing, maintaining, and understanding relationships. These deficits can include difficulty adjusting one's behavior to different social contexts, difficulty in sharing imaginative play, difficulty making friends, and lack of interest in peers.

Furthermore, ASD is characterized by restricted, repetitive patterns of behavior, interests, or activities (current or historical), manifested by at least two of the following (examples are illustrative, not exhaustive; see text):

- Stereotyped or repetitive speech, motor movements, or use of objects (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
- Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food).
- Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation

with unusual objects, excessively circumscribed or perseverative interest).

- Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

ASD symptoms must be present in the early developmental period, but symptoms may not fully manifest until social demands exceed one's limited capacities and may be masked later in life by learned strategies.

Symptoms can cause clinically significant impairment in social, occupational, or other important areas of current functioning. For a diagnosis of ASD, these impaired functioning cannot be better explained by intellectual disability (intellectual developmental disorder, or IDD) or global developmental delay, though IDD and ASD frequently co-occur. To make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication ability must be below the level expected for general development.

It is important to determine if impairment in social, occupational, or other areas of functioning occur:

- With or without accompanying intellectual impairment
- With or without accompanying language impairment
- With a known medical or genetic condition or environmental factor

### Box 1-3: DSM-5 case definition of ASD

- Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays
- Restricted, repetitive patterns of behavior, interests, or activities
- Symptoms must be present in early childhood
- Symptoms together limit and impair everyday functioning

In the context of precision, a participant asked why there is not a stronger focus on genetic testing and integrating genetic testing with therapeutics. Leventhal replied that genetic testing is very expensive and does not necessarily impact the way a patient is treated. Genetic testing should be considered if there are significant clinical indications, such as dysmorphic features, strong family history of disorder, or focal neurological findings. Furthermore, genetic testing can be helpful in assessing the risk for having more children with ASD if the patient's parents are planning on having another child or if the siblings of the patient are at reproductive age. Testing for testing's sake is not clinically beneficial, because, at present, genetic testing rarely provides actionable, clinically relevant information.

### 3.2 BEST ASSESSMENT PRACTICES FOR AUTISM SPECTRUM DISORDERS

Eapen reflected on whether the best standards of ASD assessment are consistently implemented. She argued that best practices are not being met in Australia, where the mean age of diagnosis is too late (4 years, at start of school).<sup>58</sup> Late diagnosis causes children with ASD to miss out on early intervention services that are proven to have long-term health benefits. These missed opportunities impact those with ASD, their families, even the mental capital of the entire country, she noted, stressing the importance of investigating why this failure is occurring.

Eapen outlined several factors that may contribute to the failure to achieve best assessment standards, including the age of symptom onset, diagnostic criteria and tools, and ASD awareness. She stressed that there are serious gaps in service delivery, as only one-third of ASD cases come to clinical attention. Patients who receive attention and services tend to be on the severe end of the spectrum or have complex comorbidities such as epilepsy and mental health problems. Eapen reported that among the parents of

children with ASD, approximately 13.6% note ASD symptoms very early (prior to 11 months), approximately 68.2% notice the symptoms around 11-18 months, and approximately 13.6% report loss of acquired skills. She explained that parents often disregard ASD symptoms because they can be so subtle.

Eapen emphasized the need for comprehensive assessment of patients presenting with common comorbidities, as evidenced by many young persons who are diagnosed exclusively with ADHD, despite having additional neurodevelopmental issues. In many cases, comorbidities may mask ASD, emphasizing the need for comprehensive diagnostic assessments that take into account the clinical and genetic heterogeneities among comorbidities, in which these are all part of the phenotypic presentation of the same underlying neurodevelopmental gene(s). Detailed diagnostic assessments can also counteract clinicians' expectations and diagnostic bias. Eapen reported that ASD diagnoses tend to be missed most often in patients who are high functioning, female and who have higher IQs and better adaptive skills.

Eapen next considered the function of diagnosis—"is it a means to assist or a hindrance?" She considered a scenario of a patient with breast cancer, questioning whether services would be initiated as soon as a breast lump is noticed or **delayed until a diagnosis** of breast cancer is made. She noted that the definition of a "case" and "classification" differs across different contexts, including early identification in the community (e.g. a breast lump), diagnostic classification and staging (e.g., pathology), and treatment planning (e.g. genetic profile). ASD assessment would benefit from a "breast lump" approach to early identification: health care providers should immediately refer anyone who demonstrates **early signs and symptoms** consistent with ASD for further assessment and appropriate intervention. The provision of educational support should be determined by the individual's cognitive level and functional capacity. Educational

58 Bent et al. *J Autism Dev Disord* 2015

support may be provided by a mainstream school, a special class within a mainstream school, or a special academic center. Achieving appropriate coverage of educational support will require universal developmental surveillance and rapid identification and linkage to services for students in need. Once a patient is identified, emphasis shifts to ongoing monitoring and follow up on the student's progress ("the hypertension approach"). Following the hypertension analogy, a threshold for diagnosis that (somewhat arbitrarily) demarcates risk or impairment must be determined. In diagnosing a syndrome like ASD, Eapen suggested that a diagnosis is justified if there is significant deviation from what is expected for the age and gender, if there is distress to the person or family, or if there is dysfunction characterized by impairment in any domains of functioning.

Eapen explained that developing diagnostic categories of ASD within a dimensional model may be useful in improving the diagnosis of a complex syndrome like ASD.<sup>59</sup> Hypertension and diabetes are instructive examples of clinically heterogeneous diseases with complex models of diagnosis, care, and service provision. Identifying people with borderline high blood pressure or pre-diabetes is critical for implementing prevention activities and life-style interventions early. She argued that instead of changing the definition and criteria to achieve the various goals of prevention, early identification, communication, interventions, service planning, and funding, there should be a broad, dimensional approach with further categorization and subtyping based on behaviors, neuro-cognitive profile, biomarkers, genotyping, and so forth.<sup>60</sup> Exploring links between genotypes, phenotypes, and clinical predictors of response to early intensive behavioral intervention in autism spectrum disorder.<sup>61</sup> She suggested that the diabetes

approach would be a good starting point to use as a model for improving the diagnosis of ASD and service provision. Like ASD, Diabetes is a clinically and genetically heterogeneous condition with subtypes (type 1 diabetes, type 2 diabetes, maturity onset diabetes of the young (MODY), and additional subtypes of MODY based on genotypes). Subtyping has different utility for different audiences. While communicating to the lay public and for awareness, it may be most appropriate to discuss medical conditions in general. When communicating with professional colleagues and research institutions, it may be useful and appropriate to discuss the subtypes and specific categories of clinical conditions.

### 3.3 ASSESSING AUTISM SPECTRUM DISORDERS: GLOBAL AND REGIONAL EXPERIENCES

#### 3.3.1 The Massachusetts Child Psychiatry Access Program: Model from the USA

Hesham Hamoda<sup>62</sup> described the Massachusetts Child Psychiatry Access Program (MCPAP), a publicly funded program established in 2004 to improve access to child psychiatric services. Hamoda noted that even in Massachusetts, which has the second highest concentration of child psychiatrists in the United States and one of the highest concentrations in the world, access to psychiatry services remains an issue. The goals of MCPAP are to improve the pediatricians' competencies in: screening, identification, and assessment; treating behavioral health disorders; making effective referrals for community services; and coordinating the care of patients who need community-based psychiatric and behavioral health services. MCPAP is payer-blind and provides consultation regardless of the child and family's insurance. Six regional teams provide MCPAP services to patients across

59 Eapen *Frontiers in Psychiatry* 2012

60 Eapen et al. *Frontiers in Human Neuroscience* 2013

61 Eapen et al. *Frontiers in Human Neuroscience* 2013

62 Hesham Hamoda, MD, MPH, Attending Psychiatrist, Boston Children's Hospital, Assistant Professor in Psychiatry, Harvard Medical School, Boston, MA

the state. MCPAP teams provide training and education to medical practices within their regions, either on-site or through web conferencing.<sup>63</sup> Between 2008 and 2015, the most common reasons for consult were diagnostic questions, questions regarding medication, requests for guidance about resources, and concerns about community access to psychiatric care.

MCPAP consultations begin with a telephone call from the primary provider, followed by an in-person assessment for psychopharmacology and diagnostic consultations if indicated. All face-to-face assessments result in a written consultation letter with recommendations for the referring primary care provider within two business days. MCPAP also provides resources and referrals for community services.<sup>64</sup> Satisfaction surveys indicate that most providers are satisfied with MCPAP consultations, stating that they are timely and useful.

Hamoda reported that this has now become a national model, with 32 US states adopting similar programs that have formed a coalition called the “National Network of Child Psychiatry Access Programs.” This may be a good model to adopt for improving access for ASD services.

### **3.4 ASSESSMENT IN ASD SYSTEMS OF CARE: KEY ENABLERS**

During the workshop, participants discussed key factors to enable prompt and effective assessment and diagnosis within systems of care for ASD. Willis opened the discussion by describing a plan currently under development in Dubai that will create a comprehensive diagnostic assessment for children at risk identified during ASD screening. The objectives of the comprehensive assessment (which includes clinical assessment, developmental assessment, family history, and laboratory testing) are to come to

a diagnosis (ASD or otherwise), identify any comorbid conditions, and carry out a functional assessment of the child’s strengths and weaknesses. Planned criteria for diagnosis include:

- Clinical diagnosis based on history, examination, and behavioral observations
- Completion of a validated assessment tool, administered by a trained professional
- Clinical assessments must document presence of internationally acceptable diagnostic clinical criteria (DSM-V)

Upon diagnosis, the case manager will refer the patient and family to appropriate evidence-based interventions.

Willis reported that they are considering developing a list of the required competencies for a clinic/hospital/center to be a designated autism assessment center and ensuring that only those who meet these requirements are provided funding for the assessment. Participants discussed the competencies that could be mandated for privileged providers. One suggested that speech and language assessment and intervention should be a priority, because communication is the best predictor of outcome. They suggested that, as a starting point, designated centers could be required to have specialists from clinical, developmental, or general psychology; educational psychology; and neuropsychology. Board-certified behavior analysts (BCBAs) could supervise behavioral care provided by appropriately trained technicians on a weekly basis. Designated centers could become approved sites to train local staff and offer internships. Comprehensive ASD assessment should be an inter- and transdisciplinary process that results in a comprehensive report and treatment plan to allow for effective linkage and communication with education, health, and other sectors.

<sup>63</sup> Topics include training on screening and toolkits, clinician topics (diagnostics, medications, management of specific disorders), behavioral health resource and referral, practice protocols for use of clinical guidelines and registries, and case rounds.

<sup>64</sup> Including psychiatry, psychotherapy, CBHI services, neuropsychological testing, and other services such as support groups, group therapy, social skills groups, parent education, early intervention, etc.

## 4 Early Intervention and treatment for Autism Spectrum Disorder

According to Dr. Amar Albanna, the goals of ASD interventions should be to improve the daily life (adaptive) functioning of the identified patient and his/her family as well as to help the patient develop meaningful and functional skills across school, work, home, and community settings.

### 4.1 GENERAL PRINCIPLES IN THE TREATMENT OF AUTISM SPECTRUM DISORDER

Leventhal emphasized that most children with ASD improve over time. However, there is much work to be done toward achieving the goal of allowing all children with ASD to live a fulfilling life, integrated with their community. Ultimately, experts strive to understand ASD etiologies in order to enhance treatment and prevent ASD. In the meantime, experts aim to use treatments to improve the rate at which individuals with ASD acquire social and cognitive skills and the ability to live independently and semi-independently.

According to Leventhal, some objectives in order to provide treatment are:

- Recognize the essential elements of the ASD syndrome and the criteria for ASD diagnosis
- Identify the elements of the ASD phenotype that are candidates for treatment targets
- Develop an awareness of the risks and benefits of different treatment options and strategies
- Have familiarity with integrated treatment models

Leventhal emphasized that there are no curative treatments for ASD. Since ASD is a syndrome with phenotypic and etiologic heterogeneity, individual patients

exhibit different symptoms. Thus, because treatments target symptoms, the treatment plans for different individuals are equally heterogeneous because they must address the unique ASD profile of each individual.

Gaddour summarized three major intervention philosophies for ASD. Behavioral interventions focus on learning skills through operant conditioning, breakdown of learning into small segments, and prompting. Developmental interventions focus on using developmentally appropriate skills, sharing positive experiences, learning new topics, having fun, and encouraging child-led interactions relevant to his or her interests. A strategy called Treatment and Education of Autistic and Communication related Handicapped Children (TEACCH) focuses on structuring a protected environment to maximize learning by reducing stimulation, simplifying information, and providing visual cues, for example. The goal of TEACCH is to allow the child to learn initially in a protected environment before generalizing the skills to the unprotected environment outside the classroom.

#### 4.1.1 Goal: Evidence-based treatments

Leventhal stressed the desire of the ASD expert community to implement more evidence-based treatments for ASD. Although “not all evidence is created equal,” he explained, there are standards for determining the quality of the evidence, such as Cochrane,<sup>65</sup> NICE,<sup>66</sup> and others. Evidence is graded according to a hierarchy ranking various types of studies (Figure 14):

<sup>65</sup> Cochrane Consumer Network 2018

<sup>66</sup> National Institute for Health and Care Excellence 2018

**Figure 14. Grading of evidence**

Hierarchy	Type of Study
1a	Systematic reviews of randomized clinical trials (RCTs)
1b	Individual RCTs with narrow confidence intervals
2a	Systematic reviews of cohort studies
2b	Individual cohort studies and low quality RCTs
3a	Systematic reviews of case-control studies
3b	Case control studies
4	Case series and poor quality cohort and case-control studies
5	Expert opinion

Source: Leventhal presentation at the “Systems of Care for Autism Spectrum Disorder: A Global Perspective” conference hosted by Al Jalila Children’s Specialty Hospital in Dubai, in collaboration with the HMS Center for Global Health Delivery-Dubai, April 1, 2017

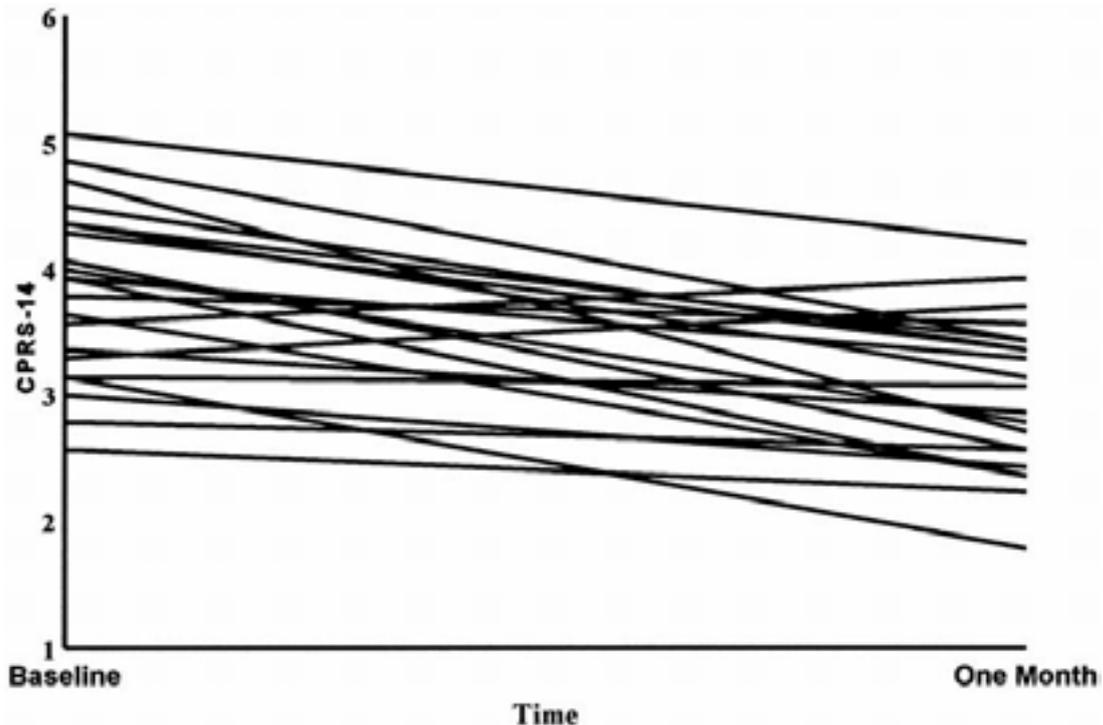
Assessing the strength of evidence requires examining multiple dimensions, Leventhal explained. The quality of methods is a function of research design, sampling, investigator bias, and confounding variables, among other elements. Statistical significance depends upon analytic techniques, tests of significance, correction for multiple comparisons, avoidance of Type I and Type II errors, and *post hoc* analyses. Clinical significance and sensitivity/specificity analyses determine the relevance of the findings, and effect size helps determine the risk/benefit ratio. The confidence interval also reflects the strength of the evidence.

#### **4.1.2 What is effective treatment?**

Leventhal defined an effective treatment as one that builds on skills, works around

limits and deficits, and takes place in a developmental context appropriate for the patient, in as natural an environment as possible. Optimal treatments have demonstrated efficacy and effectiveness, are shown to do no harm, and are constantly evaluated throughout the course of the treatment using standards established *á priori*. Group-level analyses are important, noted Leventhal, but it is also important to consider the positive impact treatment can have on a single child within that group. To illustrate this point, he cited a study that examined the varying outcomes of one treatment among different children. Each line represents an individual child’s score from baseline to the end of short-term treatment (Figure 15):

**Figure 15. Change in the mean item score on the Children's Psychiatric Rating Scale-14 (CPRS-14) with risperidone**



Source: Leventhal presentation at the "Systems of Care for Autism Spectrum Disorder: A Global Perspective" conference hosted by Al Jalila Children's Specialty Hospital in Dubai, in collaboration with the HMS Center for Global Health Delivery-Dubai, April 1, 2017; Malone et al. *J Am Acad Child Adolesc Psychiatry* 2002

Appropriate assessment is the starting point for developing effective treatment plans for ASD, Leventhal reiterated. Common deficits upon which to focus treatment include:

- Developmental delays
- Cognitive deficits: cognitive abilities, including attention and executive function
- Expressive, receptive, and social language abilities, including limited spontaneous language
- Interfering behaviors of autism: insistence on sameness, motor, SIB
- Social deficits: theory of mind, coordinating verbal and non-verbal behavior, reciprocal social behavior, interpreting social meaning, limited motivation
- Joint attention
- Experiential deficits: lack of familiarity, lack of experience, over-selectivity

Leventhal noted that people with developmental disorders may not engage much with the outside world; thus, measuring their experiential or subjective deficits is a critical challenge. Encouraging engagement in the broader community could take the form of outings to restaurants, community centers, movie theaters, etc. He suggested working with churches or mosques as a strategy for bringing ASD children into the social and religious community. Further, law enforcement also needs to better understand how to appropriately interact with individuals who have ASD.

### **4.1.3 Autism outcomes and treatment: key predictive factors**

Leventhal noted that expressive language and communicative speech (by age 5) may be the best prognostic predictors of ASD outcomes. Language comprehension and intellectual capacity as related to nonverbal intelligence are also strong predictors of ASD outcomes. Other predictive factors include adaptive function, severity of autism along the dimensions of socialization, restricted/repetitive behaviors, and aggressive behaviors.

There are a number of factors that affect an individual's response to ASD treatment, Leventhal explained. For instance, the child's ability to adapt to temporal, physical, and behavioral structures, their interest in the treatment activities, and their ability to spend time engaged in focused activity impacts their response to treatment, as do the child's abilities to tolerate exposure to typical peers, to learn specific behaviors (especially social behaviors), and to generalize skills to multiple contexts. Leventhal noted that some non-specific treatments have very good outcomes, such as developing social skills to help children operate appropriately in their social context (e.g., teaching them to hug their parents).

### **4.1.4 Minimum treatment standards and regulating standard of care**

Given the mushrooming number of private treatment centers that may or may not be employing evidence-based treatment, Fayyad asked about minimum treatment standards. Almodayfer replied that implementing ideal standards of treatment everywhere is not feasible because it would be too cost- and resource-intensive. He suggested minimum universal standards include scientific background for all service delivery centers, minimum standards for number of specialties available, and a measurable monitoring

strategy. ASD care centers must be accredited and held accountable for outcomes. Naheed suggested the following minimum standards: early screening within a national program; guidelines that national institutions should follow; and essential human resources are essential to facilitate program sustainability and cost effectiveness (moderately educated health workers can provide these services). Ad'dabbagh recommended setting minimum standards that meet professional standards and are region-specific but not logistically unattainable.

### **4.1.5 Subtyping ASD for more effective individualized care**

The most effective care is determined by a constellation of factors including an individual child's characteristics, the type of intervention (dose, type, age at starting intervention), family and psychosocial factors, and genetics. Eapen suggested that subtyping along genetic, neurocognitive, and environmental/family variables could help to match patients with the best-possible interventions and to better understand what treatment works for whom, in what context, and why it works. There are lessons to be learned regarding genotype-phenotype interactions and appropriate individualized care from fields like oncology.

While early intervention is effective, there is still considerable variability in outcomes among different intervention programs, as well as among children receiving the same intervention. The same holds for any syndromal diagnosis where there is no single, specific etiology being treated and no identified pathophysiology. Eapen explained that the developmental trajectory is shaped by a variety of inputs which may relate to the variability in outcomes of early intervention programs (Figure 16):



development will require productive cross-sectoral investment and collaboration that will pave the way for the downstream implementation of evidence-informed practices and policies for comprehensive ASD care.

#### **4.1.6 Evidence-based Interventions for ASD**

Leventhal explained that interventions for ASD must be developmentally appropriate and suited to each individual child's interests to keep him or her engaged. Major categories of interventions include:

- Speech and language therapy
- Educational programming
- Social skills training
- Behavior therapy
- Family interventions: education and parent training
- Individual psychotherapy
- Pharmacotherapy

Derby argued that evidence-based practices dictate that professionals and service delivery organizations<sup>68</sup> should ensure equal access to health care (physical and mental), education, and social services for all children and persons with ASD. This should be facilitated by the development of a local ASD team to take the lead in providing assessment, management, and coordination of the care of the child with ASD and his/her family. All health, education, and social service professionals need to be knowledgeable and competent and should receive training in comprehensive management of ASD.

#### **4.1.6.9 Behavior Therapy for ASD**

Managing a child's behavior requires developing an individualized and comprehensive plan. However, Leventhal noted, the quality of the system delivering the care is more important than the individualized plan. General behavior therapy techniques

include Applied Behavior Analysis (ABA) and Discreet Trial Training (DTT) (e.g., Lovaas Model<sup>69</sup> and Pivotal Response Training [PRT]). Key principles of ABA, according to Eapen, include Antecedent- Behavior- Consequence (ABC) format, efficacious application of behavioral teaching technique, repetition, and management of unwanted behavior. Key principles of PRT include following the child's lead, giving choices, taking turns, reinforcing the child's attempts, maintenance interspersed with acquisition, and the direct response-R+ relationship.

The output of functional behavior analysis (FBA) is a targeted behavioral intervention plan devised through structured analysis of problematic behaviors over multiple observations in different environments and situations. Leventhal explained that FBA detects behaviors that are atypical, lead to social isolation, and interfere with learning, adaptation, and participation in the environment. FBA also identifies positive and adaptive behaviors that are to be reinforced. Analysis is performed with attention to discrete behaviors as well as behavioral antecedents, behavioral objectives, and behavioral consequences.

Hamoda asked about the management of sexualized behavior in children with ASD, such as pubescent children exhibiting inappropriate sexual behavior in group settings because they lack context for controlling urges. Leventhal reported that there are no data on the use of hormonal suppression for males to decrease oversexualized behaviors and that studies on sexually aggressive predators have demonstrated that hormonal therapy does not restrict sexually aggressive urges. To best manage sexual behavior, there needs to be a plan in place to address such behaviors long before puberty.

Currently, there is minimal evidence that psychodynamic therapy is effective in ASD, according to Leventhal. However, there is evidence that Cognitive Behavioral Therapy

<sup>68</sup> National Collaborating Centre for Women's and Children's Health (UK) 2011

<sup>69</sup> Smith et al. *Am J Ment Retard* 1997

(CBT) can be effective for conditions that are frequently co-morbid with ASD, including anxiety, depression, and suicidality.

Eapen stated that there is a significant amount of data to support the potential of early intervention to affect key outcomes in ASD: “the earlier the intervention, the better the outcome.” She reiterated that biology is not destiny; the activities children engage in are either building a more social communicative brain or a more object-oriented brain. Early intensive intervention can alter the developmental trajectory to boost the social orientated networks in the brain. Genetically determined impairment in neural social reward circuitry is a biological deficit, she explained. Such deficits can increase social deprivation, which in turn leads to lack of social learning (imitation and observational learning) and, ultimately, a child who drifts to the outside of the social loop. Biological impediments to social learning can also cascade to alter the course of the child’s neural and psychological development. All children need to be engaged in social learning in order to achieve standard developmental goals, she warned.

Early intervention works through trial and error, Eapen explained. Perseverance and creativity are required to consistently engage the child in ways that elicit the needed response. ASD patients tend to focus just upon what they are seeing at a given moment with little attention to the holistic experience. This is demonstrated by abnormal eye/gaze processing, abnormal social attention, reduced attention to eye region, and failure to develop cortical face specialization (social cognitive face processing, facial memory etc.). She suggested that early intervention that enhances social attention and that emotional integration may lead to changes in neuronal circuitry formation through brain plasticity. Brain imaging has demonstrated that with early intervention, children with ASD show appropriately increased cortical activation

in the social brain areas when prompted (for example, when shown photographs of their mothers versus strangers).

#### 4.1.6.9.1 Early Intensive Behavioral Intervention: The Early Start Denver Model

According to Eapen, early intensive behavioral interventions are empirically effective.<sup>70</sup>

The Early Start Denver Model (ESDM) is a developmental-play-based program that targets social deficits by providing children with enriched social stimulation through therapists.<sup>71</sup> Elements of the EDSM include developmental play, relationship-based intervention (PRT), and applied behavior analysis (ABA). ESDM is a manualized intervention program for children aged 12-60 months, including roles for parents as well as professionals. Using the medium of play, adults capture children’s attention to engage them in learning to allow reciprocal social interaction. Target items include gaining the child’s attention; sensory social routines; dyadic engagement; joint activity routines; triangles of attention; building play skills; imagination activities; and speech development. She explained that precursors of language and social attention—joint attention, imitation, and intentional communication—are important characteristics to target in early intervention to optimize outcomes. For instance, language outcomes are positively associated with early joint attention.<sup>72</sup> Teaching principles in the ESDM model emphasize relationships and verbal/non-verbal communication in all activities and functions.

A systematic review established ESDM’s benefits for pre-school aged children.<sup>73</sup> Children who underwent ESDM delivered individually for 20 hours per week exhibited significant gains in visual processing and improvements in language abilities,

70 Makrygianni and Reed *Research in Autism Spectrum Disorders* 2010; Reichow et al. *Cochrane Database Syst RevS* 2012; Vismara and Rogers *Annu Rev Clin Psychol* 2010

71 Dawson et al. *Pediatrics* 2010

72 Charman et al. *Int J Lang Commun Disord* 2003

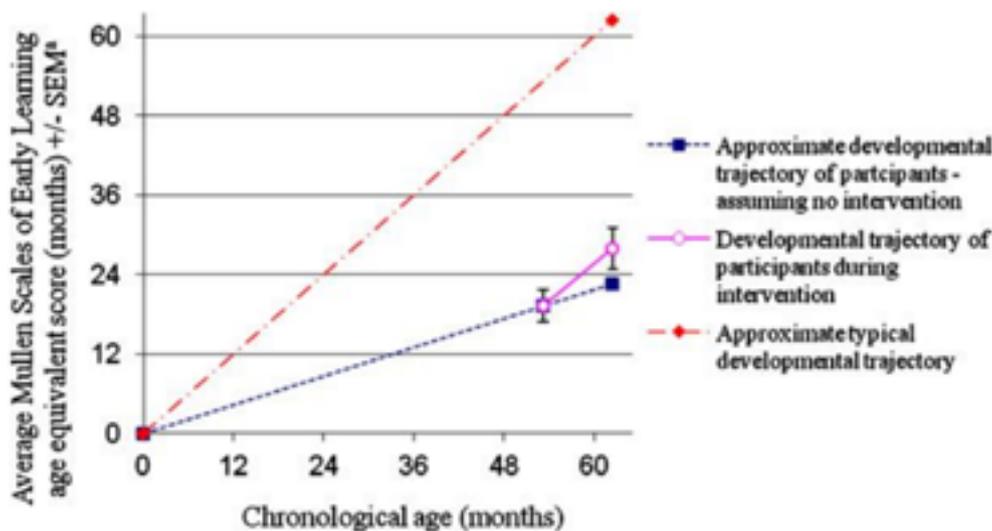
73 Waddington et al. *Review Journal of Autism and Developmental Disorders* 2016

with subsequent gains in IQ and adaptive behaviors.<sup>74</sup>

Though effective, ESDM is a resource intensive program. Fortunately, less resource-intensive methods of delivery, such as community-based group delivery models, have also proven to be effective in early intervention for individuals with ASD. The government-funded Autism Specific Early Learning and Care Centre (ASELCC) program in Australia provides ASD interventions in extended

day care center settings, with trained staff placed at different play stations through which the children rotate. Two studies<sup>75</sup> of children<sup>76</sup> with a diagnosis of ASD attending the New South Wales ASELCC found improvements<sup>77,78</sup> and observed a shift in the children's developmental trajectory toward the neuro-typical trajectory. Figure 17 shows the approximate developmental trajectory of study participants before and after group ESDM intervention, compared to a typical developmental trajectory:

**Figure 17. Developmental trajectory of ESDM participants**



Source: Eapen presentation at the "Systems of Care for Autism Spectrum Disorder: A Global Perspective" conference hosted by Al Jalila Children's Specialty Hospital in Dubai, in collaboration with the HMS Center for Global Health Delivery-Dubai, April 1, 2017; Eapen et al. *BMC Pediatr.* 2013

Even more than the severity of a child's ASD symptoms, the presence of unwanted behaviors more often results in social consequences that are destructive to the child's learning and are frequently the cause of difficulties in integrating in classroom setting. Eapen emphasized that it is crucial that these undesired behaviors come to be replaced over time with more socially acceptable behaviors.

Following the child's lead and focusing on the communicative functions of joint attention, social interaction, and practicing turn-taking are important ways to prevent and replace maladaptive behaviors. She recommended ESDM as a powerful tool for the management of unwanted behaviors by promoting a child's receptive and expressive communication skills, citing a study that linked ESDM with a

74 Dawson et al. *Pediatrics* 2010; Rogers et al. *J Am Acad Child Adolesc Psychiatry* 2012; Vismara et al. *Topics in Early childhood Special Education* 2013

75 Eapen et al. *BMC Pediatr* 2013; Vivanti et al. *J Autism Dev Disord* 2013

76 Mean age = 52.16 months (SD 5.43), majority (92%) male

77 Using group activities 15 to 20 hours per week among large groups (8-12 per room) in rotational play spaces, as well as using peer intervention opportunities for integration with typically developing children

78 Eapen & Crnec *Autism-Open Access* 2016

significant reduction in behavioral problems using parent/staff CBCL.<sup>79</sup> Another ESDM study measured electroencephalogram (EEG) activity, event-related potentials (ERP), and spectral power during the presentation of the faces versus objects. When viewing faces, children who received ESDM and typically developing children both had shorter Nc latency (attention-related ERP) and increased cortical activation (associated with improved social behavior) than the “treatment as usual” community group, which showed the opposite pattern over a year.<sup>80</sup>

With a reported prevalence of >1%, clinic based interventions are costly and resource-intensive.<sup>81</sup> Therefore, Eapen suggested taking treatment into the community and focusing on early identification and training the teachers, therapists, and parents of preschool children with ASD. She explained that sustainability will be an ongoing challenge, with all countries facing shortages in human resource. She also noted that early identification is fruitless unless a treatment system exists for referral. In environments constrained by high costs and human resource shortages, she suggested that early intervention programs (e.g., ESDM principles) instituted within childcare and preschool settings might offer a sustainable solution with significant clinical and economic benefits.

#### 4.1.6.10 Speech and language therapy for ASD

Speech and language therapy is comprised of both demand communication (gesture, vocalization, words, phrases, and reciprocal communication) and exposure to natural language at social events, at school, throughout the community, and with adults, siblings, and peers. Leventhal noted that the subtleties in speech are very important. Exposure to television and videos can be good

or bad in terms of exposure to language, he suggested, depending on the amount of time spent watching, the programs one watches, and the impact on the specific individual. Augmentative communication tools can be helpful to certain individuals who are unable to speak.<sup>82</sup> However, Leventhal cautioned that language is an essential part of social life, so continuous attempts should always be made to teach a patient to speak. Some children do not verbalize until after they learn how to type, for example. He explained that there are no pharmacological interventions that have been demonstrated to improve speech. Speech and language therapy and communication practice should be integrated as often as possible into every type of therapy and interactions across the entire day.

#### 4.1.6.11 Psychopharmacology for ASD

Psychopharmacology cannot cure ASD, reiterated Leventhal, but it can treat specific behaviors and symptoms. It can also decrease behavior problems that interfere with other interventions. The guiding principle of treatment is to “do no harm,” but risks and benefits must be balanced, as all medications for ASD may have side effects. He cautioned that just because a small amount of medication benefits a patient, more medication will not always add more benefit. Similarly, just because one medication benefits a patient, two or more medications will not necessarily add more benefit.

Restrictive and repetitive behaviors—including stereotypies, insistence on sameness, “stimming,” habits, and tics—may be treated with SSRIs, though these medications have notable side effects.<sup>83</sup> Leventhal noted that risperidone has been shown to significantly decrease irritability, but it does not treat all ASD symptoms (e.g. speech issues).<sup>84</sup>

79  $t(37) = -14.055, p < 0.001$ ; a large effect size of Cohen's  $d = -3.104$ .

80 Dawson et al. *Journal of the American Academy of Child & Adolescent Psychiatry* 2012

81 Eapen estimated the cost of early intervention for ASD at AUD 30 to 60,000 per year.

82 These include picture exchange communication systems, sign language (preferably with vocalization), and computers (e.g., laptop and Alpha Talker).

83 Fluoxetine (Prozac); sertraline (Zoloft); paroxetine (Paxil); fluvoxamine (Luvox); citalopram (Celexa); escitalopram (Lexapro); clorimpramine (Anafranil)

84 Hollander, et al. *Neuropsychopharmacology* (2004) pp1-8

Aggression and irritability symptoms may be treated with traditional neuroleptics, such as haloperidol (Haldol), trifluoperazine (Stelazine), or fluphenazine (Prolixin), or with atypical neuroleptics, such as clozapine (clozaril), risperidone (Risperdal),<sup>85</sup> olanzapine (Zyprexa), quetiapine (Seroquel), ziprasadone (Geodon), aripiperazole (Abilify),<sup>86</sup> and others. Other medications for aggression and irritability symptoms include lithium carbonate and propranolol (Inderal), and  $\alpha$ -adrenergic blockers.

Stimulants such as amphetamines<sup>87</sup> and methylphenidates<sup>88</sup> (MPH) can be used to treat attentional deficits due to ADHD in NDD, explained Leventhal. Non-stimulant ADHD treatments include Cylert (pemoline), tricyclic antidepressants, atypical antidepressants (bupropion [Wellbutrin] and venlafaxine [Effexor], SSRIs, and atypical neuroleptics). The norepinephrine agent atomoxetine (Strattera) may be effective, but Leventhal urged providers to use caution with the use of alpha adrenergic agonists, such as clonidine (Catapres, Kapvay) and granfacine (Tenex, Intuniv), due to their side effects, particularly their sedative effects.

Leventhal stated that mood disturbance and irritability in youth with ASD can be treated with mood stabilizers, including anticonvulsants (valproate [Depakote], carbamazepine [Tegretol], lamotrigine [Lamictal], neurotonin [Neurontin], and gabapentin [Gabatril]. Anxiety can be treated with anti-anxiety medications, most commonly SSRIs, yet there are currently limited data on the use of anti-anxiety medications in the ASD population. The use of benzodiazepines in persons with ASD is generally not recommended.

New medications for ASD are emerging, according to Leventhal, including GABA-active agents, mGluR5 agonists and antagonists, oxytocin, vasopressin 1A antagonist, cognitive enhancers,<sup>89</sup> and others directed at evolving biology. “Off-label” complementary and alternative/integrative treatments include sleep supplements (e.g., melatonin), diets (e.g., gluten free/casein free), supplements (e.g., omega 3 fatty acids), vitamins (e.g., B6 and magnesium), allergies (e.g., lactose), antioxidants (e.g., Vit E), and neurotransmission modulators (e.g., NAC). He warned that sample sizes have not been sufficient to promote confidence in their use, but the studies are worth watching. Providers should always ask families if they are using any additional or ‘alternative’ forms of treatment, as they may interact with other treatments. Leventhal noted the importance of discussing off-label use of medications in children, as most of the medications suggested for the treatment of ASD are not necessarily approved for use in children, thus off-label use occurs frequently. To the extent possible, guidelines for ASD evaluation and treatment grounded as much as possible on published evidence and, when published evidence is lacking, expert consensus.

Eapen cited emerging evidence that neurohormones, such as oxytocin, can be used to enhance responsiveness to social/emotional cues and face recognition, thereby improving emotional engagement and social learning. For instance, exogenous administration of oxytocin reduces activation in the amygdala in response to threat.<sup>90</sup> Oxytocin circuitry, through its connections with the dopaminergic ‘social reward’ pathways, may improve emotional recognition, social responsiveness, and social learning, memory, and cognition. Eapen is currently

85 Pharmacological Therapies for Autism Spectrum Disorder: A Review

Sheena LeClerc, PharmD; and Deidra Easley, PharmD, BCPS  
86 P&T® • June 2015 • Vol.40 No.6

87 Dexedrine (DEX); methamphetamines; Adderall; Adderall XR; Vyvanse

88 Ritalin [and other short acting methylphenidates (MPH)]; Ritalin SR; Ritalin LA; Concerta; Focalin (dextrorotary MPH); Metadate CD; Methylin ER; MPH patch; Quillivant XR/Quillichew

89 Arricept (donepezil); Exelon (rivastigmine); Namenda (memantine); Reminyl (galantamine)

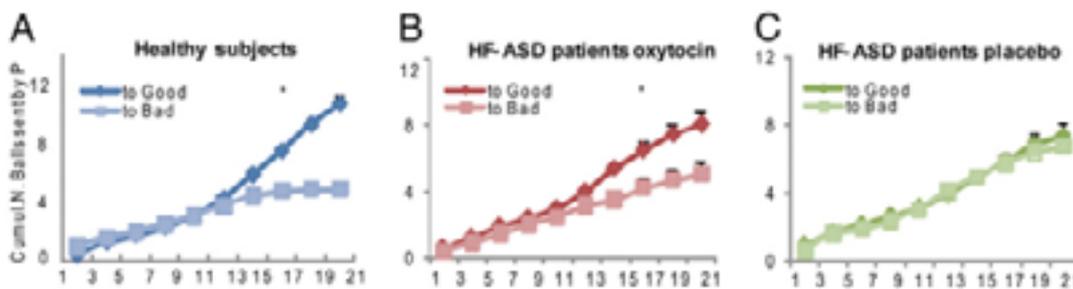
90 Kirsch et al. *Journal of Neuroscience* 2005

involved in a trial of using oxytocin compared to placebo prior to delivery of ESDM. Figure 18 demonstrates the role of oxytocin in social functioning by examining the impact

of oxytocin on trust responses of subjects to the behavior of 'good' or 'bad' partners in interactive social game over time:

**Figure 18. Promoting social behavior with oxytocin in high-functioning autism spectrum disorders**

Elissar Andari<sup>a</sup>, Jean-René Duhamel<sup>a</sup>, Tiziana Zalla<sup>b</sup>, Evelyn Herbrecht<sup>b</sup>, Marion Leboyer<sup>b</sup>, and Angela Sirigu<sup>a,1</sup>  
<sup>a</sup>Centre de Neurosciences Cognitives, Unité Mixte de Recherche 5229, Centre National de la Recherche Scientifique, 69675 Bron, France; and <sup>b</sup>Institut National de la Santé et de la Recherche Médicale U 841, Department of Psychiatry, Hôpital Chénavier-Mondor, 94000 Creteil, France



Figures show changes in Trust responses of subject to the behavior of 'good' or 'bad' partners in interactive social game, over time

PNAS 2010

Source: Eapen presentation at the "Systems of Care for Autism Spectrum Disorder: A Global Perspective" conference hosted by Al Jalila Children's Specialty Hospital in Dubai, in collaboration with the HMS Center for Global Health Delivery-Dubai, April 1, 2017; Andari et al, Proc Natl Acad Sci 2010

#### 4.1.7 Non-evidence-based treatments and interventions for ASD

Non-evidence-based "fad" treatments are rampant in ASD; Lillienfeld noted that "there is a propensity of certain interventions to endure in the practice community well after researchers have discredited them."<sup>91</sup> Dr. Paul Offit<sup>92</sup> remarked about ASD care: "It's a cottage industry of false hope." "Taking advantage of parents' desperate desire to do anything to help their children is the lowest form of quackery," Offit stated. Albanna

reported that most parents of children with ASD seek out between 4 and 7 interventions at any given time, but many of those may not be evidence-based and may even have harmful effects.

Complementary and alternative medicine (CAM) refers to medical theories and techniques based on traditional medicine that are used with (complementary) or in place of (alternative) conventional medicine. Albanna reported that 50%-90% of families of children with ASD use CAM treatments at some point, compared with 30% of the general

91 Lillienfeld et al. Evidence-Based Communication Assessment and Intervention 2014

92 Dr. Paul Offit, Professor of Pediatrics at the Children's Hospital of Philadelphia, USA and author of "Autism's False Prophets"

population.<sup>93</sup> However, parents may not share information regarding their use of CAM with their child's doctor due to concerns about disapproval, or simply because the healthcare provider did not ask or is not knowledgeable about CAM.

Leventhal warned that there are many purported treatments for ASD that have no evidence or negative evidence to support their effectiveness. Such treatments that may not be dangerous include: vitamin supplements, mineral fast forward, floor time, sensory integration therapy, and psychoanalysis. Treatments that have proven to be ineffective and even dangerous include: chelation, steroids, secretin, hyperbaric oxygen, stem cell therapy, ozone therapy, and high dose vitamins/minerals. Chelation therapy—the removal of heavy metals from the body—is a particularly hazardous treatment that can cause death.

Khaled Kaldry<sup>94</sup> asked about the importance of exposing non-evidence-based treatments, especially those that can be harmful. A participant explained that there are three aspects of treatment: evidence based treatments that have available funding through insurance programs, non-standard behavioral therapy, and therapies that have been proven to be completely ineffective. He called for a clear recommendation against the use of the third type, cautioning that families are spending too much money on treatments that “have no shred of evidence.” Willis observed that minimum standards for interventions are variable. Accordingly, the primary health care sector must be engaged in the delivery of essential care and the quality of care provided must be monitored by the government. Quality oversight for home-based care, the most prevalent form of therapy, is a particular challenge. Naheed agreed that regulating the standard of care is very important, but raised questions of who will regulate, who will be regulated, and how regulation will occur. She noted that the set of

indicators for monitoring progress in ASD care will vary across societies that have different expectations (for example, settings where mental health is a priority versus settings where mental health has historically been neglected).

## **4.2 EDUCATIONAL, SOCIAL SKILLS, AND SUPPORT INTERVENTIONS**

### **4.2.1 Educational Programming for ASD**

Leventhal provided an overview of educational programming options for children with ASD. He recommended integrating children into the mainstream educational community to the extent that it is possible without being too disruptive to other children. Models for educational integration include self-contained, inclusion, pull-out, in-class special services, a combination of models, and structured teaching (e.g., TEACCH). Leventhal advised that children should start school at the preschool level and attend for the typical duration. In terms of the number of hours per day, he suggested as long a schedule as the child can tolerate, as there is no specific amount of time proven to be optimal. The learning models applied depend on a child's cognitive abilities; options include language-oriented models, functional academics, following the child's interest, and directed learning. Rote learning methods can be effective in teaching speech, language, behavioral, and social skills.

A participant asked about the feasibility of a regional plan that maintains the current number of specialized ASD treatment centers while shifting the majority of care to the mainstream education system. Gaddour suggested that while mainstreaming a child's care is a long-term goal, a critical mass of expertise is required at the outset. The argument Gaddour suggested is that ASD centers can provide opportunities to develop the field experience necessary to function in

93 Politte et al. *Current Treatment Options in Psychiatry* 2015, Whitehouse *Journal of Paediatrics and Child Health* 2013, Politte 2015, Wong et al. *Journal of Autism and Developmental Disorders* 2006, Hanson et al. *Journal of Autism and Developmental Disorders* 2007

94 Khaled Kaldry, Consultant Psychiatrist and Lead Clinician, Mosley Service, Abu Dhabi, UAE

a mainstreamed system. Ahmed Al-Ansari<sup>95</sup> advised that the answer is not to build more specialized ASD centers, which are costly and lead to longer waiting lists for treatment. Hamoda explained that, in his region, they are working with schools and teachers to provide as much support as possible in their own settings for children with ASD and other mental health difficulties.

#### 4.2.2 Social Skills Training for ASD

Leventhal explained that most initial social skills are learned by rote learning and can allow children to participate in their communities more successfully. Structured curricula are essential for social skills training, and social groups can be a very beneficial supplement. Social learning can take place in individual and group settings at home and/or in the community, in schools, or in public areas. Specific social learning programs include Social Stories (Carole Gray), Floor Time (Greenspan), Social Thinking (Michelle Garcia-Winner), video modeling (Scott Bellini), Relationship Development Intervention (RDI) (Gutstein), and the Early Start Denver Model (ESDM) (Rogers).

#### 4.2.3 Role of Child Mental Health Services in ASD

Harper explored the role of mental health services for children with ASD. He noted that child and adolescent psychiatry, like other medical specialties, is founded on the ethics of commitment to the patient, scientific inquiry, and teaching. Child and adolescent psychiatry differs from other disciplines, however, in that troubled children require a greater amount of care and consideration, above and beyond psychoactive medications. He sketched three aims for child mental health services:

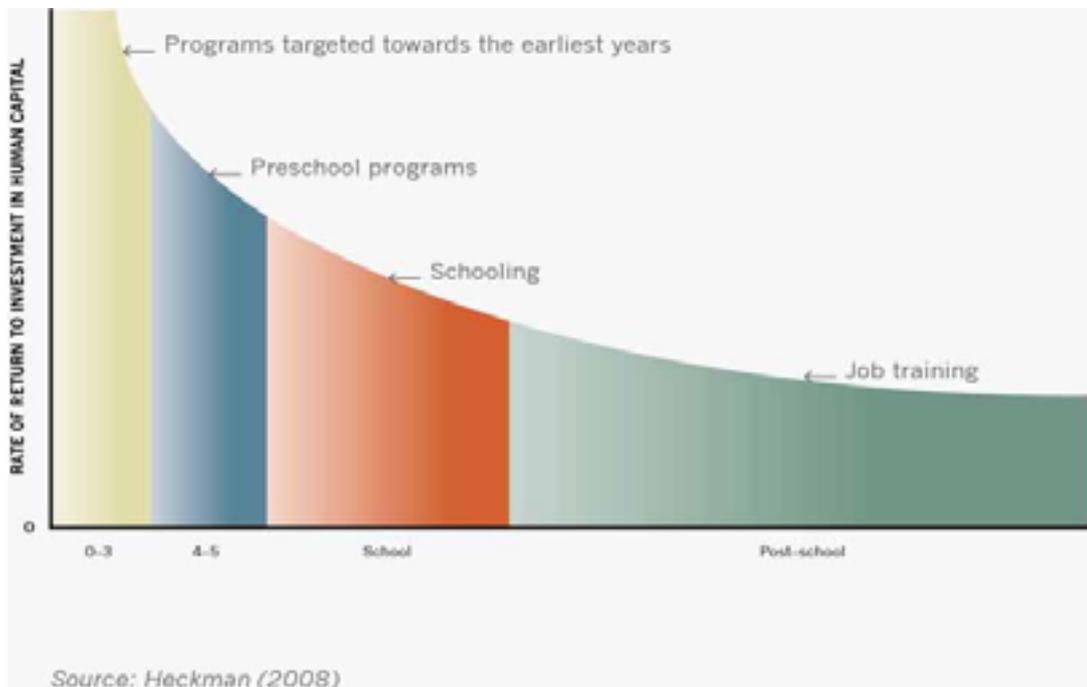
- promoting positive, long-term health outcomes (holistic, not just physical health)
- considering the child's experiences and the experience of his or her family
- distributing costs per member per year across all systems participating in care, including costs related to physical health, mental and behavioral health, special education, and residential costs<sup>96</sup>

Harper advocated for a comprehensive approach to childhood development like the one described by James J. Heckman, who argued that the earliest interventions yield the highest rates of return (Figure 19):

<sup>95</sup> Ahmed Al-Ansari, MBChB, FRCPC, College of Medicine and Medical Science, Arabian Gulf University, Bahrain

<sup>96</sup> Harper noted that residential planning is critically important and requires decisions about whether the person will be cared for at home or in an institution.

**Figure 19. Effectiveness of interventions**



Source: Harper presentation at the “Systems of Care for Autism Spectrum Disorder: A Global Perspective” conference hosted by Al Jalila Children’s Specialty Hospital in Dubai, in collaboration with the HMS Center for Global Health Delivery-Dubai, March 31, 2017; Heckman Econ Inq 2008

Harper noted that for people with ASD, costs extend beyond the financial. To illustrate, he referred to a recent Lancet article<sup>97</sup> in which the author describes the daily struggles faced by a young boy with fetal alcohol syndrome to complete simple day-to-day tasks. Moreover, the author contends that Aristotle’s definition of virtue excludes those with developmental conditions.

Harper defined the concept of categorical diagnosis: looking at who a person is—including their strengths and challenges—and encouraging those around them to talk about “life vision” following the assessment. This includes anticipating transition points when a person “ages out” of certain services. Furthermore, many families worry about what will happen to their child when parents pass away. Belfer noted that financing mechanisms can be inadequate to facilitate a smooth transition, but recommended providing vocational training coupled with a low-cost,

self-sustained residential program where individuals with ASD can safely participate in program development. Regarding continuity of care for children with ASD, Eapen contended that resources must be appropriately distributed. This includes leveraging existing resources and structures, such as school systems and pediatric primary-care services, and subsequently improving those resources, to provide a clear pathway for those who would benefit from ASD services.

#### **4.2.4 Parent Training and Support**

Providing family support is a critical part of intervention, noted Leventhal. ASD education must center not only on the patient’s nuclear family, but also on the extended family and the community-at-large. Structured parent training may involve education in behavior management and implementing structures at home for schedules and safety. Parent and family support may be provided directly by care providers and/or through

<sup>97</sup> Carel Lancet 2017

**Box 1-4. Evolving perspectives of child psychiatry**

Harper considered the evolving role of child psychiatry in influencing how ‘troubled’ children are perceived by society and in providing those children with a voice and with agency. Society’s perception of children has undergone a sea change over time, from children being considered miniature adults to childhood being considered a distinct and respected phase of life. The voice of the child has also evolved, from the idea that “children should be seen and not heard” (19<sup>th</sup> century) to “patient’s voice and choice” (late 20<sup>th</sup> century) to the present-day concept of “nothing about me without me.” Current perspectives in psychiatry,<sup>1</sup> Harper explained, include objective-descriptive, narrative, empathic diagnosis, and recovery stories (including self-understanding). Strategies to amplify the voice of the child include scientific progress, codifying patients’ rights,<sup>2</sup> and empathetic/sympathetic understanding. To truly ‘hear’ the voice of a child with ASD requires a sympathetic view that is based on understanding the mechanism (science) and empathic diagnosis (how the child feels). The child should be seen as an agent—not just an object—and should be engaged in shared narratives.

**Box 1-5. What do families want for their children with ASD?**

Dr. Hanan Darby provided an overview of what families want for their children with ASD<sup>3</sup>:

- Easy access to assessment and treatment services
- A team of trusted professionals able to help them
- Access to a variety of interventions
- Support, education, and training
- Ability to live with dignity and as much independence as possible
- To be a part of their community and wider society
- To be understood and supported by professionals
- To be respected for who they are by a knowledgeable public

support groups. Derby concurred about the advantages of training and educating parents; the involvement of parents and caregivers is essential to effective ASD intervention, because of their prominent role in shaping the environment and experiences of the child or individual in their care.

**4.2.4.12 Building Blocks of Parent Support**

Low-resource settings present a host of challenges in carrying out interventions,

noted Gaddour, such as the limited numbers of facilities and trained professionals. Staff training can be expensive and when it is available, it may not be culturally appropriate. Interventions are time consuming and international guidelines recommend a high provider-to-child ratio that may not be practically or culturally feasible in the local context. Gaddour contended that working with parents can have a large impact across settings and at all resource levels. Working with a child’s parents ultimately leads to

a better prognosis for the child, because parents are the ones who care for the child on a daily basis, they know their own child better than anyone, and they are dedicated to the care and development of their child. Engaging with parents can also help them to accept their child's diagnosis and deal with the emotional burden of having a child with ASD. Parents should be engaged during the diagnostic process and provide tools and education to help improve their child's communication abilities and reduce their challenging behaviors. Gaddour explained that parents need to understand that autism is a developmental process rather than a fixed disability, and that interventions can help. Parents, teachers, and other caregivers can contribute to a child's treatment if they are educated and given the opportunity to be involved.

Parents of children with disabilities go through stages of grief before accepting the diagnosis, Gaddour noted, and parents are more resilient when can take actions and see tangible results. He reported that parents of children with ASD tend to have more communication issues than parents of children with other types chronic conditions, so they need support in learning how to apply teaching and interventional techniques at home to improve their child's basic, social, and symbolic communication skills. He recommended using visual and practical explanations, explaining the benefits of role play and modeling, and providing parents with clear instructions on how to work with their children at home in a creative, flexible way. He cautioned that when applying parent support strategies in low-resource settings, it is important to observe how parents work with their children and tailor parental support interventions appropriately. It is also important not to pressure parents into excessive use of services, he noted. Gaddour concluded that parental support in low-resource settings can be very effective if parents are provided with an optimistic but realistic prognosis for their children, especially

when equipped with clear and simple evidence-based interventions.

#### **4.2.4.13 Major Depressive Disorder among Mothers of Children with ASD in Bangladesh**

Naheed explained that parenting a child with ASD can have negative impacts on the parents' quality of life. Rates of maternal depression are high among mothers of children with ASD, who tend to serve as their child's primary caregiver. In fact, the prevalence of depression among mothers of children with ASD is higher than mothers of children with other developmental disorders. A systematic review has suggested that the prevalence of depression among Bangladeshi adults is between 6.5% and 31%, with rates higher in females. However, the burden of depression among mothers of children with ASD has not yet been explored in Bangladesh.

Naheed presented the results of a cross-sectional 2015 study—the first research on ASD in Bangladesh. The study was designed to estimate the prevalence of depression among mothers of children with ASD in urban areas and to assess their quality of life. The study population<sup>98</sup> was assessed for depression and quality of life, using validated instruments. The average mother in the study was around 27 years of age at the time of the child's birth, had an income higher than average, and was generally highly educated but unable to work outside the home because she needed to care for the child. Children in the study were mostly male, and the majority had no siblings. The children's performance generally improved after they began schooling, with an average gap of 6 years between diagnosis and school admission. Naheed noted that monthly expenditures to support a child with ASD were typically very high.<sup>99</sup> Accordingly, mothers with more than one child were not able to spend as much on support for their child with ASD. Many mothers reported needing help at home for childcare and home-training programs to continue the

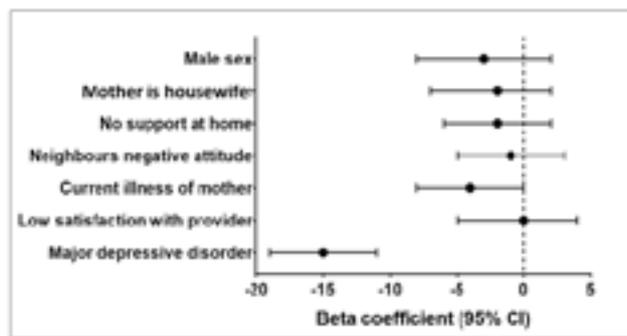
98 388 mothers of children with ASD (aged >3 years) from 6 schools in Dhaka city providing ASD care

99 Total cost per month for an autistic child, *mean (SD)*: USD 183 (201)

child's curriculum after school. Other mothers highlighted the need for special schools, community services, and special government-run programs for children. Some mothers choose to remain isolated in the home and are not willing to seek help with childcare from the community. The study found that around 45% of mothers (N=173) had major depressive disorder (MDD) and 26% currently (N=101) had MDD, even though many of

the mothers were not aware that MDD even existed. Predictors and factors contributing to maternal depression included having a male child, being a housewife, having no support at home, negative attitude of neighbors, physical illness, and low satisfaction with provider. Quality of life was lower among women with MDD in the study (Figure 20):

**Figure 20. Impact of major depressive disorder on mother's quality of life**



Applied Linear regression model ; Statistical significance at  $p < 0.05$



Source: Naheed presentation at the "Systems of Care for Autism Spectrum Disorder: A Global Perspective" conference hosted by Al Jalila Children's Specialty Hospital in Dubai, in collaboration with the HMS Center for Global Health Delivery-Dubai, March 30, 2017

According to Naheed, the study concluded that the prevalence of depression is high among mothers of children with ASD and negatively impacted the mothers' quality of life. Expanding access to mental health services for mothers and increasing support at home in the form of childcare and social services may reduce maternal depression rates among this population, she advised. Strengthening systems of care for ASD in Bangladesh will require more research to identify cost-effective solutions to reduce maternal depression and improve quality of life. Although the data may not have captured mothers who do not have access to ASD services, the study did capture baseline data about maternal depression and generate credible evidence on how to better support mothers of children with ASD. Naheed looks forward to translating research

into policy in Bangladesh, noting that the International Center for Diarrheal Disease Research in Bangladesh has collaborated with ASD experts to develop a parental training module. She also shared that efforts are underway to draft a strategic national plan and introduce mental health service for mothers in schools. Naheed emphasized the public health importance of expanding mental health research in Bangladesh, stressing that research is essential to demonstrate the feasibility of introducing maternal home-based mental health training and mental healthcare into ASD care systems. Mothers are vital to the care of children with ASD, especially in countries like Bangladesh that lack sufficient ASD service. Given the appropriate support and mental healthcare, Naheed affirmed that mothers can be strong

advocates and educators for their own children.

## **4.2.5 Interventions for ASD: global and regional experiences**

### **4.2.5.14 Clinic Model of Care: Achievements and Challenges Child and Adolescent Mental Health; Hamad medical Corporation, Qatar**

Dr. Hanan Derby explained that the Child and Adolescent Mental Health-Hamad Medical Corporation (CAMHS-HMC) in Qatar saw an increase in the number of ASD referrals (15-30 per week, with 3-6 cases of suspected or known ASD) within the first year it was open in 2016. Children were being referred due to challenging behaviors, delayed speech, mental health difficulties, school problems, and social difficulties. Mapping the existing local services revealed high demand and great need. Many families had difficulty accessing services, the private sector care was unaffordable for many, and accordingly, many children were not receiving appropriate care. Very few services were available to meet the increasing demand for accessible and affordable ASD diagnosis, assessment, and intervention.

Derby concurred that the preponderance of evidence indicates that early identification and early intervention can maximize the progress of children with ASD.<sup>100</sup> However, evidence-based research also indicates that effective ASD interventions provided for older children, adolescents, and beyond can also improve outcomes. Given the trends observed in Qatar, the CAMHS team sought to streamline the assessment process such that all children and young people receive an equitable assessment in a timely manner. The CAMHS-ASD team<sup>101</sup> consists of child and adolescent psychiatrists (consultants and specialists), a speech and language therapist, an occupational therapist, nurses with additional input from a developmental pediatrician, and a clinical

psychologist (adolescent medicine). The team carries out diagnostic assessment in the social communication clinic twice per month, provides a feedback report, offers information about appropriate services and support available, and provides and organizes interventions and care in multiple therapeutic domains.

Achievements thus far, according to Derby, include providing assessments for patients through 18 years of age, developing an evidence-based practice comprising multidisciplinary assessments, creating effective partnerships, establishing a clear yet tailored clinical pathway and protocol, delivering therapeutic interventions, providing support and education to patients and their families, and offering professional training and development. An ongoing challenge is the lack of collaboration across the health, education, and social care sectors. Furthermore, there is a lack of information about existing services and many patients must go through multiple services that do not communicate with one another. Other challenges include social stigma for patients and families, lack of services for adults with ASD, limited parental support following the diagnosis, and deficits in data management systems, education, training, and evidence-based practices.

## **4.3 TREATMENT, EDUCATION, AND SUPPORT IN ASD SYSTEMS OF CARE: KEY ENABLERS**

Willis provided an overview of the Dubai plan for early intervention, treatment, education, and support for children who receive a diagnosis of ASD after comprehensive assessment. Planned goals of intervention(s) include improving communication and play skills, facilitating greater adaptive functioning and skills, decreasing non-adaptive behaviors, and promoting cognitive and social functioning.<sup>102</sup> Planned community-based

100 Dawson & Osterling 1997; Myers *Expert Opin Pharmacother* 2007; Volkmar *J Autism Dev Disord* 2014

101 The clinician in lead of the assessment team is responsible for developing clear policy and protocols for the autism service pathway, staff training, and monitoring the progress of the clinic, and developing a new social communication clinic protocol, among many other duties.

102 Planners are considering defining an evidence-based Minimum Treatment Package using international guidelines

interventions will span early childhood learning centers, specialized and residential care centers, and home and respite care, with case managers responsible for monitoring, follow-up, and advocacy.

Participants discussed how interventions need to be safe and family-centered and should ensure the continuity of care across different settings throughout the lifetime of patients with ASD. In Dubai, as in elsewhere, practitioners peddling non-evidence-based treatments remain a huge problem. Participants suggested addressing this by convening an expert panel to develop guidelines on intervention effectiveness and efficacy that are revisited and updated regularly; these guidelines can then be disseminated to professionals, families, and communities so they can be informed consumers. Participants also discussed penalizing non-evidence-based practitioners with malpractice sanctions and/or loss of licensing and funding. Such guidelines must be updated regularly.

Key considerations in developing longitudinal treatment, education, and support mechanisms for children with ASD include the intensity and duration of interventions, the age at which the child receives each intervention, and setting of the intervention (center/clinic or natural environment such as home, early learning center, and home). Further considerations include managing comorbidities, promoting inclusion, and providing support and education for families and communities-at-large. A participant noted that some children with multiple comorbidities may not be served in all locations because their cases are too complex and the location may not have sufficient resources to help the child. Leventhal noted that about 5% of treatment seekers are “high flyers” who consume disproportionate amounts of resources. Eapen explained that in Australia, complex cases, especially those with medical

co-morbidities, are referred to the Children’s Hospital for a thorough assessment and possible inpatient admission. Depending on the outcome of the assessment, they are referred to relevant specialized programs or services. For families who are further away from these specialized centers, the hospital links the family to local resources and offers an individualized care pathway and multiple options for treatment. Participants recommended using outcome principles as the basis for recommended interventions, including:

- Goals of the intervention
- Age at which the child receives each intervention
- Intensity and duration of interventions
- Setting of interventions: center, clinic, or natural environment such as home, early learning center, and home
- Promoting inclusion
- Managing comorbidities
- Mechanisms for operationalization: programmatic or policy level interventions

Types of interventions to consider include:

- Intensive behavioral interventions
- Structured teaching
- Communication/speech therapy
- Occupational therapy (sensory integration)
- Pharmacological interventions (for irritability, ADHD, seizures, etc.)
- Evidence-based and approved complementary and alternative interventions

To ensure continuity of care across different settings, participants recommended linking care in the home with the care provided in special centers. Home-respite care should be

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and to be included as part of covered services in the basic benefit package, at a price that is both sustainable and will attract additional high-quality supply to the market. Minimum requirements for providers of the minimum package will be set to ensure that only providers who meet these requirements are privileged to receive post-assessment referrals and be funded for their care.

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considered to provide additional assistance families, especially considering that in many places, patients who would be in residential care are cared for at home due to cultural standards, stigma, or guilt.

In terms of programmatic interventions, tools, and training, participants suggested defining privileged providers based on an established minimum-standard benefits and interventions package to attract additional supply (users and providers) to the market. Training should be intensive and based on the acquisition of skills to implement the programmatic tools. Trainees also need to be provided with the justification and context for early intervention. Programmatic tools for other developmental programs can be adapted for ASD, but must be adapted to ASD (for example, the way language is used). Participants suggested improving the broader system of services by mapping and integrating existing providers from the public and private sectors, as well as linking with relevant agencies from other sectors.

Education and social inclusion are key pillars in ASD systems of care, noted participants. Participants advocated for trying to integrate children with ASD into mainstream education when possible, while keeping in mind that children with ASD benefit from individualized programming. Every child has a right to access education services, so it is important

to ensure that a diagnosis of autism does not become the basis for discrimination (even in schools that are interested in moving toward inclusion). Appropriate support needs to be provided to all educators, including those in early childhood learning centers, schools, and vocational, alternative and tertiary-level education.

Willis explained that, in Dubai, as part of the Dubai Disability Strategy, the Dubai Inclusive Education Policy Framework outlines procedures and 10 standards of educational practice to promote best practices in educational inclusion such as admission, participation and equity to quality education for all and to promote identification, early intervention. They are also considering the establishment of a quality mark for compliant schools, as well as enforcing compliance with laws that mandate equitable educational access. Schools will be provided with a practitioner education toolkit with evidence-based guidelines and expected standards of practice for how to support children with ASD in the school environment. Participants discussed the importance of building social inclusion and family supports into the systems of care for ASD to foster self-determination and independence in the child as well as to empower the families (through sibling and peer support groups, for example).

## 5 Regional Experiences in Developing ASD Services and Systems of Care

### 5.1 MAGNITUDE OF UNMET NEED FOR ASD SERVICES IN GCC

Ahmed Al-Ansari provided an overview of ASD services in the region of the Gulf Cooperation Council (GCC) to demonstrate the magnitude of unmet needs. He explained that interest in ASD in the GCC region began in the 1990s. Most ASD services are government funded, though there has been a spike in the number of privately owned centers. Still, existing services are not sufficient to satisfy the demand, primarily due to the shortage of trained staff and the fact that services are almost exclusively available in urban areas. With the exception of Bahrain, most countries lack a unified, clear, and accessible diagnostic protocol for ASD. Epidemiological studies are available in many GCC countries, but community-based prevalence or program evaluation studies are generally not available. Civil autism organizations have been established in all GCC countries, but they lack strategic plans.

#### 5.1.1 Bahrain

Al-Ansari reported that Bahrain has five private ASD care centers in which the government subsidizes 80% of costs of recurrent services. The country has seen an increase in the number of non-government-supported, private, commercialized centers. Some children in Bahrain are integrated into mainstream schooling. There were around 500 patients with a registered diagnosis of ASD in 2016. Diagnoses must be registered in order to receive the government funding for treatment. Al-Ansari estimated that around 1 in 4 autism cases are not registered. A Bahrain-specific study estimated the prevalence of ASD to be 4.3 cases per 10,000 population.<sup>103</sup> He reported that the mean age at diagnosis has

dropped considerably, reflecting increasing access to services.<sup>104</sup>

#### 5.1.2 Kuwait

Kuwait is considered a leader in establishing ASD services within the GCC. The country has a government-funded autism center, as well as other private centers. Al-Ansari reported that very few studies on ASD have been carried out in Kuwait, despite being the best provider of ASD care compared to countries in the region.

#### 5.1.3 Oman

In Oman, ASD services have lagged behind other GCC countries, but the government supports both publicly managed centers and privately managed centers. Around 900 cases of ASD are registered, although Al-Ansari estimated that only around 20% of children with ASD are receiving care (others are on waiting lists to receive care or are not yet diagnosed). There is limited integration of children with ASD into the mainstream education system. Despite the lack of service provision, there have been several publications about ASD in Oman (e.g., refuting false beliefs about autism), although the validity of a recent prevalence study has been questioned.

#### 5.1.4 Qatar

In Qatar, the Shafallah Center has been serving children with ASD since 1999 and a new autism center recently opened in 2015. There are also small private centers that provide ASD services, and some children with ASD are integrated into the mainstream school system. Al-Ansari reported that there have been a few studies of ASD in Qatar focusing on quality of life for caregivers, but more research is needed to estimate total prevalence in the country.

103 Al-Ansari & Ahmed *Eastern Mediterranean Health Journal* 2013

104 Another study found that mothers of children with ASD and adolescents with ASD were more likely to report anxiety symptoms and depressive symptoms, respectively.

### 5.1.5 Saudi Arabia

Yasser Ad-Dab'bagh<sup>105</sup> noted that virtually no services exist for adults with ASD in Saudi Arabia.<sup>106</sup> Many cases remain unidentified, due in part to the lack of services, but conservative estimates suggest that there are between 200,000-350,000 ASD cases in Saudi Arabia, more than 110,000 of which are children. Until recently there was no public discussion of autism or advocacy for services,<sup>107</sup> but that is changing slowly. Planned initiatives to develop services for children and adolescents with developmental disabilities have not yet come to fruition due to economic and political upheaval. Lack of quality of services, capacity, and sufficient number of trained staff remain ongoing barriers. Al-Ansari reported that Saudi Arabia opened the first Autism Center in the GCC (Jeddah Autism Center) in 1993. Additionally, a charitable society for autism provides consultations to 3000 families. Studies on ASD in Saudi Arabia have estimated the prevalence of ASD to be between 1.4-29 per 10,000 people and reported that 67% of people surveyed were convinced that ASD could be cured or the child would grow out of it.<sup>108</sup> Another study found that most parents reported using non-medical treatments for their children with ASD.

### 5.2 DEVELOPMENT OF SYSTEMS OF CARE FOR ASD IN DUBAI

Dr. Sandra Willis explained that the Government of Dubai's Executive Council developed the Dubai Disability Strategy, a vision and overall strategy for the Emirate of Dubai covering 6 thematic areas to be achieved through innovation and strategic partnerships. Disability support is mainstreamed in the Dubai Disability Strategy (DDS), a plan enacted into law in 2014 which promotes a paradigm shift from a medical model to a rights-based model of disability: "It is every child's right to health; it is every child's right to education." The DDS vision is for Dubai to be "an inclusive, barrier-free, rights-based society that promotes, protects, and ensures the self-determination of persons with disabilities" with a mission to implement inclusive policy and best-practices that mainstream disability and ensures access to opportunities on an equal basis with others. The outcome of the strategy will ensure equal opportunities, maintain social cohesion, build social capital, and minimize social exclusion through the "My Community...A City for Everyone" framework to empower and ensure the full rights of persons with disabilities by removing barriers and building inclusive systems, thereby realizing Dubai's vision of a Disability-Friendly City by 2020 (Figure 21):

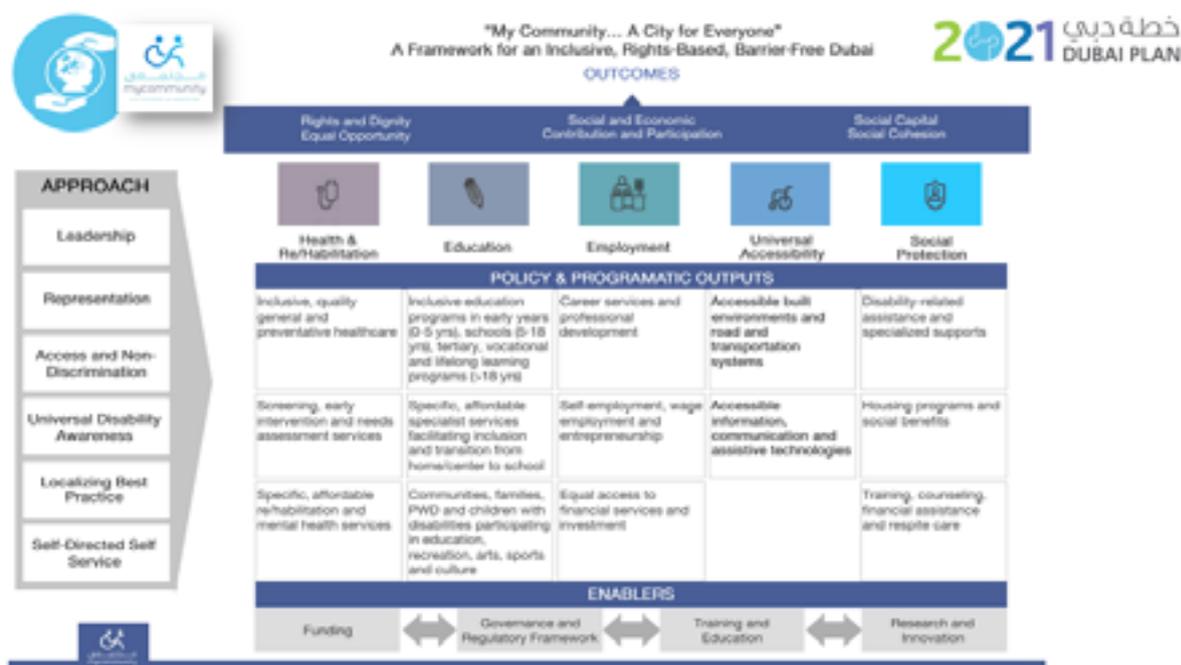
<sup>105</sup> Yasser Ad-Dab'bagh, MD, FRCPC, King Fahad Specialist Hospital, Consultant Pediatric Neuropsychiatrist, King Fahad Specialist Hospital, Dammam, Saudi Arabia

<sup>106</sup> Cases are potentially higher than international average because Saudi Arabia is, as he described it, an "international laboratory for neurodegenerative disorders."

<sup>107</sup> He cited a 2013 WHO report found that only 15 of the 25 child psychologists in Saudi Arabia are able to perform complete assessments for ASD.

<sup>108</sup> Faheem et al. *BMC Genomics* 2016

Figure 21. Dubai Disability Strategy



Source: Willis presentation at the "Systems of Care for Autism Spectrum Disorder: A Global Perspective" conference hosted by Al Jalila Children's Specialty Hospital in Dubai, in collaboration with the HMS Center for Global Health Delivery-Dubai, March 30, 2017

Willis provided an overview of the gaps and persistent challenges related to the system of care for ASD in Dubai:

- Lack of awareness
- Entrenched social stigma and exclusion
- Late or inadequate identification and diagnosis
- Lack of access to quality, evidence-based, and affordable treatments/interventions
- Inadequately regulated treatments/interventions, which can potentially lead to non-evidence-based and harmful treatments
- Fragmented services with no clear referral pathway, due to the absence of a strategic and integrated approach to respond to the health, social, or economic challenges
- Limited licensed specialist workforce (particularly Arabic speaking)

- Limited inclusive mainstream, vocational, and lifelong education opportunities
- Limited of access to employment
- Inadequate social habilitation

However, she noted that there are many strengths to be leveraged moving forward in Dubai, including strong political will and increasing community awareness about ASD. The tertiary-level Al Jalila Specialty Children's Hospital is now open with a dedicated autism unit. Private, clinic-based services have burgeoned in response to community demand, and community-based, dedicated ASD and disability-specific centers continue to fill service gaps. A small number of educators are now more willing to enroll high-functioning children with ASD.

A 2017 creative lab or "accelerator" event held a session called "My name is Ibrahim: Dubai System of Care for Autism" served as a platform to gather experts and key

stakeholders in health, education and social sectors to develop a plan for the Dubai Systems of Care for ASD. “My name is Ibrahim” is named after a young adult with ASD living in Dubai whose parents are strong advocates for ASD. The session encouraged the development of a system that ensures optimal identification and diagnosis of persons with ASD, access to effective ASD care and interventions, and inclusion of people with ASD in the community. The system would be situated within an integrated system of health, education, and social care to enable efficient and effective collaboration between different stakeholders, thereby leading to the development of integrated policy and

programmatic interventions. The think tank event had three deliverables: to draft the Dubai Declaration on Autism (Figure 22), to develop the Dubai System of Care for Autism 100-day plan (Figure 23), and to encourage research on ASD prevalence and efficacy studies of evidence-based ASD interventions and supports.

Willis explained that the system of care for autism will be supported by six key pillars of infrastructure: governance and leadership; regulations and standards; accountability and evaluation; financing; public engagement and political will building; and professional development.

**Figure 22. Dubai Declaration on Autism**



**MY COMMUNITY... A CITY FOR EVERYONE  
DUBAI DECLARATION ON PERSONS WITH AUTISM**

We, as a group of leaders, policy makers, health actors, civil society, advocates, family and service user representatives, and other stakeholders convened in Dubai on 20-21 March 2017 to participate in Dubai Plan 2021 organized “futureXchanges” Think Tank entitled “My Name is Ibrahim” were

- Inspired by the esteemed leadership including Dubai’s Crown Prince His Highness, Sheikh Hamdan bin Mohammed bin Rashid Al Maktoum and His Highness Sheikh Mansoor Bin Mohammed Al Maktoum, Chair of the Higher Committee on the Rights of Person with Disabilities,
- Aligned with the Universal Declaration of Human Rights and the Convention on the Rights of Persons with Disabilities ratified by the UAE in 2008, as well as resolutions adopted by other forums, in particular in the United Nations General Assembly on Autism,
- Reiterating the provisions of Constitutions and Legislation such as the Law No. (2) of 2014 Concerning the Protection of the Rights of Persons with Disabilities in the Emirate of Dubai established to safeguard against discrimination and social exclusion of people on grounds of an disability or condition, and securing the provision of the basic necessities of life, in particular, education and medical care and rehabilitation,
- Noting that developmental disorders such as Autism are being increasingly recognized as severely interfering with developmental, educational and social attainments, and bring significant economic costs to families and societies,
- Aware that autism is a lifelong neurodevelopmental spectrum disorder that is often characterized by impairments in social interaction, verbal and non-verbal communication, repetitive behavior, interests and activities,
- Concerned that, despite increasing evidence documenting the effectiveness of intensive early interventions in improving the overall functioning of the child and long-term outcomes, children and families in need are often identified later and have poor access to services thereby not receiving adequate treatment and care,

- • Deeply concerned about the prevalence and high rate of autism and other developmental disorders in our communities and its consequent developmental challenges to long-term health and social care as well as its tremendous social and economic impact
- • Recalling that people with autism and other developmental disorders along with their families often face major challenges associated with stigma, isolation and discrimination that may lead to social exclusion, neglect and abuse
- • Recognizing further that attention received by policy makers and public health experts and consequent allocation of resources have so far been inadequate to address the treatment gap for autism and other development disorders, and stronger concerted efforts and required
- • Acknowledging efforts undertaken by governments and local/global health actors to tackle the problem which led to increased public concerns for autism and other developmental disorders
- • Inspired further, by a vision that all individuals with autism and other developmental disorders ought to receive adequate and equal opportunities to enjoy health, educational and employment opportunities and achieve their optimal developmental potential and quality of life, be self-determined and participate in, and contribute towards, society as outlined by the Dubai Disability Strategy

We, as a group of leaders, policy makers, health actors, civil society, advocates, family and service user representatives, and other stakeholders convened in Dubai on 20-21 March 2017 to participate in Dubai Plan 2021 organized “futureXchanges” Think Tank entitled “My Name is Ibrahim” and drafted a Dubai Declaration on Autism a detailed below.

In Keeping with the My Community... A City for Everyone initiative committed to transforming Dubai to be a disability-friendly city by 2020, Dubai will establish a Dubai System of Care for Autism that plans to:

Adopt this Declaration with the objective of promoting stronger and coordinated actions in Dubai towards the development of a SYSTEM OF CARE FOR AUTISM throughout the lifespan.

Unite key government departments, disability specific organizations (DPOs), private providers, academic, and key [self] advocates to establish an AUTISM WORKING GROUP promoting a supportive legislative and policy environment for the provision of care and the social inclusion of people with autism and their families.

Task the appropriate parties the priority actions as outlined in the Dubai System of Care for Autism 100-Day Plan to realizing the goal of establishing an seamless integrated system of care for autism and other neurodevelopmental disorders in Dubai that includes increasing AWARENESS of autism and the rights of persons with autism; developing a HEALTH PLAN from early detection, assessment, treatment and intervention; developing an EDUCATION PLAN to include students with autism in early years, schools, vocational, alternative, and tertiary level education; and developing a SOCIAL INCLUSION PLAN to promote the self-determination, independence and inclusion of people with autism while ensuring the families are supported and empowered.

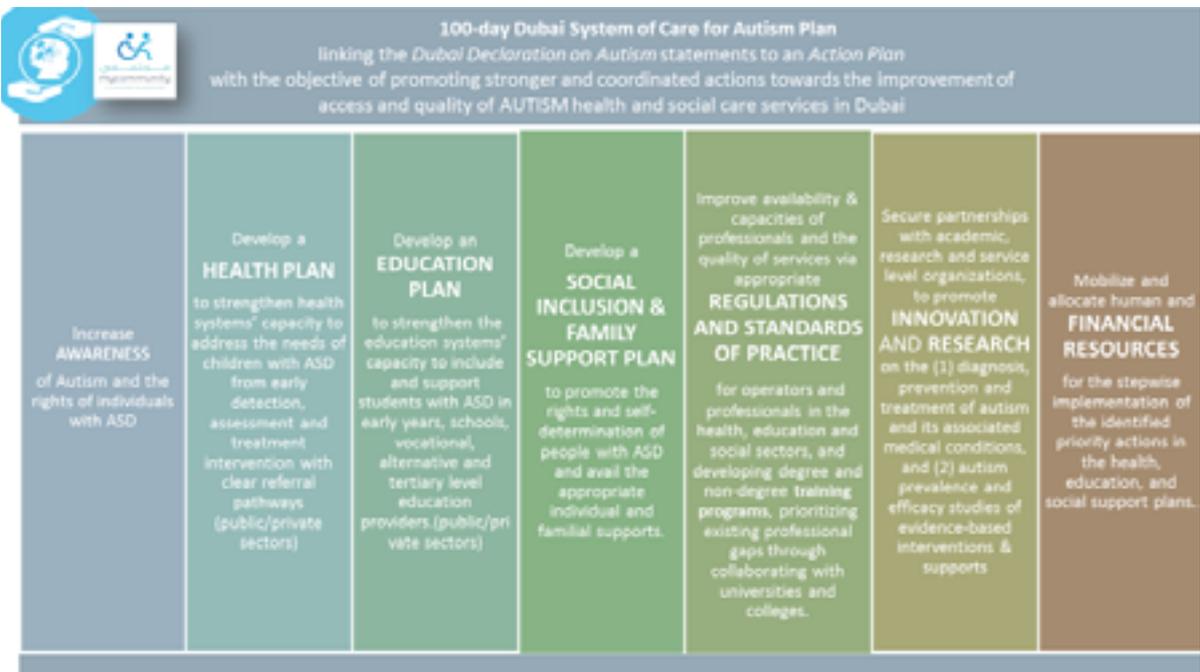
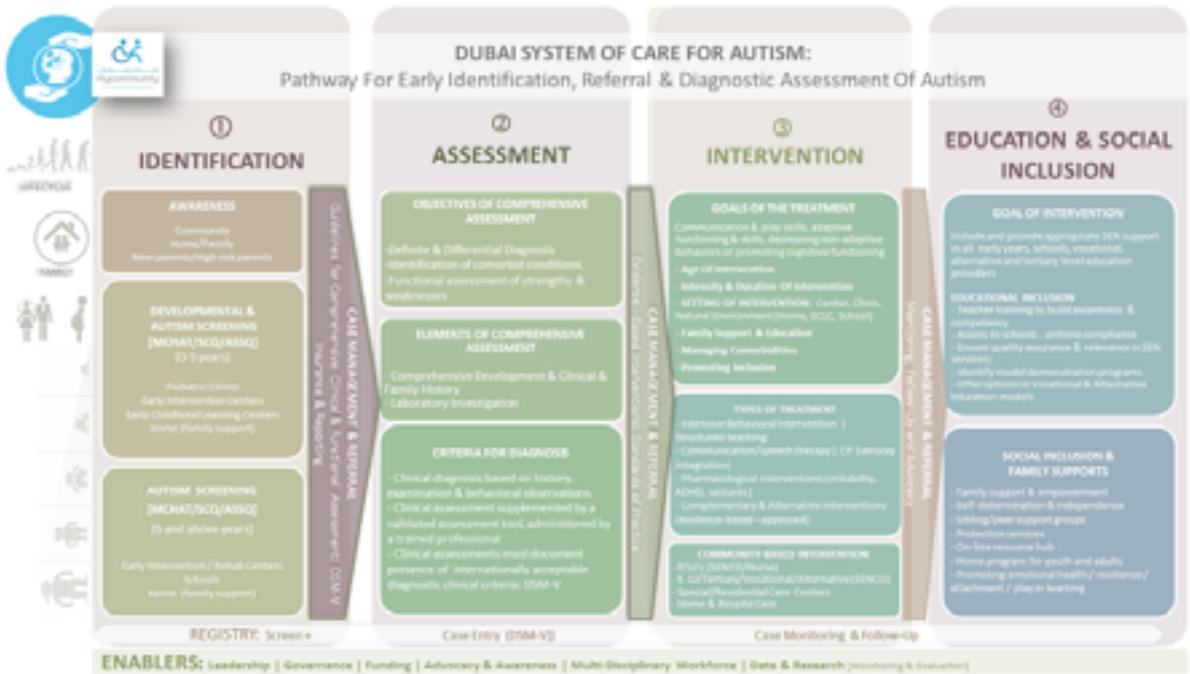
Improve availability & capacities of PROFESSIONALS and the quality of services via appropriate REGULATIONS AND STANDARDS OF PRACTICE for operators and professionals in the health, education and social sectors.

Secure partnerships with relevant international, regional and local academic, research and service level organizations to promote INNOVATION and RESEARCH on the care, supports and habilitation services in the context of and integrated systems of care model.

Mobilize and allocate human and FINANCIAL RESOURCES for the stepwise implementation of the identified priority actions in health, educations, and social settings.

*Source: Willis presentation at the Post-conference symposium “Systems of Care for Autism Spectrum Disorder: A Global Perspective” hosted by Al Jalila Children’s Specialty Hospital in Dubai, in collaboration with the HMS Center for Global Health Delivery-Dubai, April 2nd, 2017*

**Figure 23. Dubai System of Care for Autism**



Source: Willis presentation at the Post-conference symposium "Systems of Care for Autism Spectrum Disorder: A Global Perspective" hosted by Al Jalila Children's Specialty Hospital in Dubai, in collaboration with the HMS Center for Global Health Delivery-Dubai, April 2nd, 2017

### 5.3 DEVELOPING NATIONAL GUIDELINES FOR ASD: THE QATAR EXPERIENCE

Qatar faces a set of challenges with respect to ASD that overlap with many other countries: stigma, insufficient data, poor rates of early diagnosis, inadequate provision of services, poor quality of interventions, lack of service integration, limited availability of trained staff, and lack of adult services. Dr. Muhammad Waqar Azeem<sup>109</sup> described the development of the Qatar National Plan on ASD. This plan was due to be released in April 2017 as part of the country's National Mental Health Strategy (2013-2018). The first ASD stakeholders' meeting took place in 2013 and led to the creation of a public-private national working group with six task forces: awareness, early recognition/screening, assessment/diagnosis, interventions, education, and transition to adulthood. Families of children with ASD, and particularly mothers, have played an important role in developing the plan. The vision of Qatar's National Autism Plan is that individuals with autism can:

- Live in a society that knows about and understands ASD (awareness)
- Have their needs identified early
- Have access to timely, reliable diagnosis and assessment
- Have access to timely, individualized intervention and services
- Have access to appropriate education
- Have access to social and cultural activities
- Have access to relevant information, so they and family members are well informed, empowered and feel supported.
- Be supported in their transition into adulthood
- 

### 5.4 AUTISM SERVICE DEVELOPMENT IN SAUDI ARABIA

Dr. Omar Almodayfer, MD<sup>110</sup> described two initiatives for establishing ASD services at King Abdulaziz Medical City, Ministry of National Guard-Health Affairs (KAMC-MNGHA) and the Human Development Center (HDC). One major project is the establishment of a Child Mental Health Program at a tertiary care center (King Abdullah Specialized Children Hospital) where service is delivered by a specialist team from the Child Psychiatry Services Department comprised of a Consultant Psychiatrist, Assistant Psychiatrist, Senior Psychologist, Senior Family Therapist, Assistant Psychologist, and Case Manager. The first step of the Program after referral is a child mental health screening which includes an interview; multiple standardized screenings (behavioral, emotional, parent/family, unstructured observation, psychosocial, life functioning, risk of suicide or self-injury); parental consent and education; and unstructured observation. The second step is a comprehensive assessment of the child by the multi-disciplinary specialist team through semi-structured/structured interviews, and gathering information about backgrounds, symptoms, and functioning, as well as a battery of psychometric tools and family assessment tools. Children diagnosed with ASD receive a specialized, evidence-based treatment plan from the ASD Child Mental Health Program. Almodayfer stressed the importance of providing training for parents so they can communicate more effectively with their preschool-aged children with ASD, with planned expansion to include training for parents of older children with ASD. Overall, the program's ethos is that children with ASD can develop far beyond the usual expectations when treatment is well designed to meet their needs. The ASD program integrates multiple objectives:

109 Muhammad Waqar Azeem, MD, DFAACAP, DFAPA, Chair, National Autism Working Group, Co-Chair WISH Autism Forum, Chair, Department of Psychiatry, Sidra Medical and Research Center, Doha, Qatar

110 Dr. Omar Almodayfer MD, FRCPC Head, Mental Health Department, KAMC- MNGHA, CEO, Human Development Co., Saudi Arabia

- Empowering children's parents so they can feel more confident in caring for their child
- Implementing evidence-based methods of Applied Behavior Analysis that have proven effective for individuals on the autism spectrum
- Promoting social communication, language development, positive relationships, social skills, emotion- and self-regulation, and positive behavior management
- Enhancing social responsiveness, sensory processing, functional motor skills, and social-emotional factors

Almodayfer reported that the Program has been fairly successful thus far. Data show that a greater number of mothers than fathers attended the three-hour weekly parent group. They will continue to monitor progress of the Program based on treatment plan objectives and outcomes.

The second project Almodayfer described, initiated in 2007, is a network of human development centers and schools, day program centers, specialized classrooms, and special education schools. Currently, the network encompasses nine program centers and two schools, with 1600 children utilizing the services daily. Some of the challenges they encountered include a lack of specialized clinicians, restriction of diagnostic services to major cities only. There was some confusion about the difference between ASD assessment and ASD diagnosis, which led to long waiting times for assessments and access to intervention services. The network established that diagnosis can be done remotely but assessment needs to be performed in the centers, as rehabilitation cannot be done without comprehensive assessment. Efforts to help surmount these challenges have included raising awareness among clinicians and the public, as well as employing electronic screening and mobile ASD teams.

Lack of expertise among professionals (special educators in non-urban areas, speech and OT specialists, psychologists, and social workers) has caused major variations in services for persons with ASD and thereby has posed a challenge in scaling up access to these services. Accordingly, there are ongoing efforts to recruit and train international experts in ASD and assistants. The program is also developing an online training academy based on the competency model for each specialty. They have also created a rehabilitation clinical pathway with Rehadox, the dynamic database that runs their programs. The program initially employed therapeutic approaches such as TEACCH and LOVASS, but eventually shifted their focus to individualized ASD due to challenges arising from comorbidities. Children who improve after their initial care program go on to attend a specialized kindergarten (mainstream curriculum plus a special education pathway) to prepare them for school. The success of the school highlighted the importance of low-intensity mainstream classroom projects for children with high-functioning ASD. Safety became an issue as programs progressed, so they developed safety protocols including GPS devices, an RDIF control system, and a fleet management system for buses. The program's current goals are to serve 10,000 children daily by 2022, to expand to small- and medium-size cities, to continue investing in local staff training, and to expand the age range of children served.

## 5.5 DEVELOPMENT OF ASD SERVICES IN PAKISTAN'S AGA KHAN UNIVERSITY

Aisha Mian<sup>111</sup> described the experience of Aga Khan University (AKU) in Karachi in developing ASD services in Pakistan. For a population of 200 million, 60 million of whom are children under the age of 14 years, there are only 4.5 trained child psychiatrists, 7 qualified speech therapists (of inconsistent quality), and very few occupational therapists.

<sup>111</sup> Ayesha Mian, MD, Associate Professor and Department Chair, Department of Psychiatry, Aga Khan University Hospital, Karachi, Pakistan

Difficult, mountainous terrain in the northern part of the country impedes service delivery outside of urban areas. Prior to the AKU initiative, there were three autism centers in the country, located in major cities, though the centers' resources were very limited and services not consolidated. There were two child psychiatrists at AKU covering both child and adult clinics and only sporadically seeing children with autism. Despite obvious resource shortages, AKU faced mounting pressure to develop comprehensive in-house services. With support from a donor interested in developing services specifically for autism, the AKU Child Learning and Behavior Clinic was launched in 2016, with the aim of having children at risk visit a speech pathologist, behavioral psychologist, and psychiatrist in a single visit, resulting in a report generated within 2 weeks. Group assessment allows parents to meet with all of the child's therapists at once. Within two months of the launch, 21 patients had been assessed by the Clinic. In addition to service provision, the Clinic also seeks to raise awareness about ASD and support parents. This led to the creation of a parent support group Autism Parents in Action (APact), with plans to expand by starting similar groups in other regions. The system is moving forward with a three-pronged approach: awareness and advocacy, research and education, and service development. Next steps include service mapping, working toward the removal or scaled reduction of fees, developing programs to increase awareness in schools, developing of a special needs curriculum, instituting screening camps for autism and related conditions, and implementing a marketing campaign to raise awareness.

## 5.6 FACILITIES FOR TREATMENT OF CHILDREN WITH ASD: EXPERIENCE FROM TUNISIA

Naoufel Gaddour shared the experience of treating children with ASD in Tunisia, a

country in North Africa with a population around 10 million. Education and health systems in Tunisia have improved in recent years due to compulsory schooling, expanded immunization efforts, and better access to primary health care, symptomatic of the shift in public health priorities towards improving quality of life. The nuclear family is the primary model in Tunisia, but national strategies and programs lag far behind the needs and the expectations of families. Until 2015, there was no specific mention of ASD and it was subsumed in the "mental handicap" category. Gaddour was involved in the first systematic screening for ASD in Tunisia in 2009.<sup>112</sup> The screening required international collaboration to translate and validate the Modified Checklist for Autism in Toddlers (m-CHAT), which was then administered to parents during a child's second immunization at 18 months.<sup>113</sup> The Scale of Pervasive Developmental Disorder in Mentally Retarded Persons Scale (PDD-MRS)<sup>114</sup> and the Childhood Autism Rating Scale (CARS) have also been translated into Arabic and validated, and have already been used to identify missed cases.

Gaddour suggested that child psychiatrists adopt a strategy to improve awareness about ASD among healthcare professionals and preschool educators (e.g., advocacy through media), as well as training for teams working on the front lines of ASD care (social workers, speech therapists, school staff, etc.). Most ASD diagnoses are made by approximately 60 child psychiatrists who practice in the country. Considering this shortage of clinicians, clinics are often too overwhelmed to complete a thorough evaluation. While an increasing number of ASD cases are presenting at the clinic, there are many false positive referrals (Gaddour estimated around 25%) initiated by parents who are not confident in their pediatrician's reassurances against the presence of ASD in their children. The age of first referral has dropped from around 4 years

<sup>112</sup> Bedoui & Gaddour 2009

<sup>113</sup> Among 866 evaluated children, three (3.5%) were diagnosed with ASD after clinical evaluation (108 were referred after the first m-CHAT).

<sup>114</sup> Kraijer a& de Bildt *J Autism Dev Disord* 2005

of age to around 2 years of age, meaning that early identification is improving outcomes.

Greater awareness around ASD has led to improved and earlier diagnosis as well as better outcomes, noted Gaddour, but improved screening has not been coupled with improved intervention services. Tunisian law theoretically guarantees free healthcare and appropriate education for every disabled child. In practice, the state sponsors NGOs to provide services for people with disabilities rather than providing them directly, leading to incomplete coverage of services. The state subsidizes less than one-third of the average cost of ASD services; parents must pay the remaining costs. Special education centers are generally the preferred mode of education for children with special needs, but, until the year 2000, there were only two facilities for ASD. The Tunisian Association for the Promotion of Mental Health is a national NGO founded by psychiatrists, parents, and volunteers focused on activities to raise awareness and reduce stigma. In 2004, they developed a psychoeducational center for ASD, staffed by psychiatrists, psychologists, special educators, therapists, etc. The center faced a number of barriers to providing services to persons with ASD: an evidence-based intervention was needed, but there was no consensus worldwide; educators were not trained to perform behavioral interventions; and educational materials were not available or were contextually inappropriate. Thus,

the center decided to focus first on creating strong relationships with the children and then working to teach new behaviors and skills. They provided an Individual Educational Plan for each child, based on a thorough evaluation and adjusted to their developmental level and family context. The centers program's use both developmental and behavioral approaches with very simplified, structured activities.

Recently, many special facilities for ASD have opened in the private sector, providing greater choice to parents. However, Gaddour cautioned that these private facilities may be lacking in key areas: appropriate trained staff to deliver interventions, a concerted strategy/vision, leadership, and sustainability. Private facilities may also provide treatments that are not based on empirical evidence.

A national network for autism was established in Tunisia in 2009 and a national strategic plan was proposed to the government. However, the government is resistant to adopt the plan due to financial concerns. Despite important strides made in diagnosis and recognition, ASD services remain fragile, poorly structured, and lacking in a common vision. Moving forward, according to Gaddour, will require learning from successful examples, applying cost-effective management models, and finding innovative ways to provide services for adults with ASD.

## 6 Conclusions and Recommendations

Every system is perfectly designed to obtain the results it gets, reflected Harper. He introduced Heifetz's perspective on change, which differentiates between technical challenges, which can be solved by expert knowledge, and adaptive challenges, which require new learning. Level I (technical) problems are easiest to resolve because the problem definition is clear and a leader or expert provides a solution (e.g., a Zika vaccine). At Level II (technical and adaptive) the problem definition is clear, but the solution requires new learning and both the leader and the followers are responsible for the solution. Level III (adaptive) challenges are the most difficult to resolve, because the problem definition, solution, and implementation require new learning and the responsibility for the solution resides with the followers. Harper cited a *New England Journal of Medicine* article that provides an instructive comparison of health care systems in different countries.<sup>115</sup> He noted that, as a lifetime condition, ASD differs substantially from other types of health events. As an advocacy tool, he suggested presenting two cases: one in which a child with ASD was well-served and one in which the child was not well-served. It is also effective to compare children with "ordinary" ASD and children with severe ASD side-by-side. He also suggested adopting a "syndemic" perspective (as explored in a recent *Lancet* series)<sup>116</sup> to approach ASD in the Middle East. He explained that the concept of syndemics involves clusters of diseases that co-occur in populations and addressing syndemics involves examining their biological, social, cultural, political, and psychological interactions and determinants. Addressing ASD will require a similarly broad and comprehensive approach.

Leventhal reiterated that ASD is a complex syndrome that must be addressed with a complex strategy that addresses several

fronts including basic science, epidemiology, identification, recruitment, and training human resources. This strategy must also be supported by public policy. All components are required for the system to succeed, even if they are not accomplished at the same speed. Munir cautioned: "do not expose yourself beyond what you are trained to do. You're not saviors of the world. You need to build and train an interdisciplinary workforce for collaborative work to tackle challenges, and to work within the model of professional conduct with best quality care based on evidence-based training." Leventhal also cautioned that the most difficult task is ensuring that the system has appropriately trained people and utilizes evidence-based treatments. Eapen advised that it is important not to overburden the system at the outset, which can undermine sustainability and lead to staff burn-out. Capacity building, piloting, and context-specific evaluation continuously at every step is important for long-term success. Leventhal warned that demand needs to be demonstrated while simultaneously trying to meet that demand. It is important to spread the message that "by making our children healthier, we make our country more economically stable." Furthermore, developing evidence to support services and interventions is just as crucial as developing services. For example, pediatricians were reluctant to screen mothers for maternal depression because they did not know where to refer the mothers who screen positively for treatment and therefore considered screening unethical. However, if the need is not identified, there will never be sufficient services and interventions available to help the patients who could benefit greatly from them. This dilemma underlines the need to work on both sides of the problem at once – develop care systems while developing the evidence to support them.

115 Morrissey et al. *International Health Care Systems* 2015

116 Mendenhall *Lancet* 2017

Harper underscored the importance of focusing on a future vision of ASD care at the policy level. This vision can be obfuscated by discussion of downstream details of providing ASD care, but it is important to focus on the details of how to achieve that vision. Key policy-related questions to consider include: What is the consensus, at the policy level, regarding how individuals with ASD are perceived? What is your country's goal in terms of service provision, quality of life, and community integration for those with ASD?

## 6.1 RECOMMENDATIONS

Creating a comprehensive System of Care for autism that is coordinated, person-centered and promotes continuity of care improves the outcomes for those “navigating” the often-fragmented system. Evidence provided by the conference suggests that such coordination results in a multi-component approach that is likely to achieve better results than those reliant on a limited set of discrete strategies, particularly given that the optimal ASD identification and interventions and treatments involve a multi-disciplinary, evidence-based approach.

‘Individualizing’ the system approach to ASD requires a shared understanding and commitment from all stakeholders that individuals with ASD ought to receive adequate and equal opportunities to enjoy health, educational, employment and social opportunities and achieve their optimal development potential and quality of life, be self-determined and participate in, and contribute towards, society.

Therefore, it is highly recommended that developing a system of care for ASD ought to ensure the highest standard of care for the identification, assessment, intervention and inclusion of people with ASD within an integrated system of health, education and social care that will enable efficient and effective collaboration between decision makers, stakeholders, and beneficiaries,

thereby leading to the development of coherent integrated policy and programmatic interventions that:

- Adopt models aligned with international best practices, which can be customized to each country, culture, and context in adopting a suitable system that consolidates coordination of resources in order to provide efficient care and reduce cost.
- Unite all key stakeholders to establish the critical mass needed to promote a supportive advocacy, legislative and policy environment for the provision of care and the social inclusion of individuals with ASD, their families and allies.
- Task the relevant parties with their respective roles and responsibilities in realizing the goal of establishing a system of care for ASD that includes, but is not limited to:
  - Increasing awareness of autism and rights of people with autism
  - Developing a continuity of care health plan utilizing evidence-based approaches across the different phases from early detection, assessment to treatment and intervention
  - Developing an educational plan to include students with ASD in inclusive educational opportunities and promoting their social inclusion to promote independence and self-determination.
  - Providing family support services given the rate of mental health and economic burden on families of individuals with ASD
  - Ensuring biological, clinical, social, functional aspects using evidence-based tools in order to reach a comprehensive and accurate diagnosis and provide a treatment plan that improves outcomes and family wellbeing.
- Improve the availability and capabilities of the professionals and the quality of services via appropriate policies,

- regulation and standards of practice guidelines for operators and professionals in all related sectors.
- Secure key partnerships in government and non-governments agencies to provide intersectorial coordination and commissioning, and to provide training and global partnerships to promote research and innovation in the care and supports for the system of care for ASD.
- Mobilize and allocate human and financial resources for the implementation of the plan keeping in mind the increased prevalence of ASD represents an increase uptake in service utilization that requires the development of a robust evidence-based and cost-effective system

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# Appendices

## **APPENDIX 1. LIST OF PLANNING COMMITTEE MEMBERS**

Ammar Albanna  
Bennet Leventhal  
Gordon Harper  
Hesham Hamoda  
Kerim Munir  
Myron Belfer  
Sandra Willis  
Valsamma Eapen

## APPENDIX 2. LIST OF CONFERENCE PRESENTERS/PARTICIPANTS

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## APPENDIX 3. CONFERENCE AGENDA

### Day 1: Thursday March 30th, 2017

- 8:30 – 9:00 Registration
- 9:00 – 9:30 Systems of care: A global perspective  
*Myron Belfer*
- 9:30 - 10:00 Global prevalence and burden of t ASD  
*Bennett Leventhal*
- 10.30 – 11:00 Screening versus surveillance for ASD at the population level: A case for proportionate universalism  
*Valsamma Eapen*
- 11:00 - 11:30 Coffee Break/Networking
- 11.00 – 11.30 Autism Spectrum Disorder: A global framework for action  
*Kerim Munir*
- 11:30 - 12:00 Q & A and Panel Discussion
- 12:00 – 12:55 Opening Ceremony: National Anthem  
Opening remarks — *HE Khalid Alshaikh*  
Harvard — *Dr. Salmaan Keshavjee*  
EMACAPAP — *Dr. John Fayyad*  
AJH — *Dr. Ammar Albanna*  
Lemonade Movie
- 12:55 - 14:00 Prayer and Lunch Break
- 14:00-14:20 Regional Perspectives (1)  
Developing a system of care for Autism in Dubai  
*Sandra Willis & Ammar Albanna*
- 14:20 – 14:40 Regional Perspectives (2)  
The status of ASD services in KSA: Successes and challenges  
*Yasser Ad-Dab'bagh*
- 14:40 – 15:00 Regional Perspectives (3)  
Facilities for treatment of children with ASD: Experience from Tunisia  
*Noufel Gaddour*
- 15:00 - 15:15 Coffee Break/Networking
- 15:15 – 15:35 Regional Perspectives (4)  
ASD clinical assessment pathway - Qatar and UK experience  
*Hanan Derby*
- 15:35 -15:55 Regional Perspectives (5)  
ASD services in Bangladesh: A brief overview focusing on maternal mental health  
*Aliya Naheed*
- 15:55– 16:15 Q&A & Panel Discussion (Regional Perspectives Panel)
- 16:30- 19:30 Research seminar small group meeting

## Day 2: Friday March 31th, 2017

- 8:30 – 9:00 Registration
- 9:00 – 09:30 Role of child mental health services in ASD  
*Gordon Harper*
- 09:30 - 10:00 The Massachusetts Child Psychiatry Access Program: A model from the US  
*Hesham Hamoda*
- 10:00 – 10:20 Panel Discussion and Q & A
- 10:20 – 10:50 Coffee Break/Networking
- 10:50 - 11:20 Standards of comprehensive assessment in ASD  
*Bennet Leventhal*
- 11:20 – 11:45 Best assessment practices for ASD — ASD in Australia “are we meeting best standards?”  
*Valsamma Eapen*
- 11:45 – 12:00 Panel Discussion and Q & A
- 12:00-13:30 Friday Prayer and Lunch Break
- 13:30 – 13:50 Regional Perspectives (1)  
Developing national guidelines for ASD: The Qatar experience  
Qatar National Plan on Autism Spectrum Disorder  
*Waqar Azeem*
- 13:50 – 14:10 Regional Perspectives (2)  
Autism Spectrum Disorder services in Arabian Gulf Region: The magnitude of unmet needs  
*Ahmad AlAnsari (Bahrain)*
- 14:10-14:30 Regional Perspectives (3)  
ASD services in Pakistan  
*Aisha Mian*
- 14:30-14:45 Coffee Break/Networking
- 14:45-15:05 Regional Perspectives (4)  
Autism Spectrum Disorder: Regional and local perspectives (Abu Dhabi, UAE)  
*Ahmad Al Mai*
- 15:05-15:25 Regional Perspectives (5)  
Building blocks of working with parents of ASD children and care providers  
*Noufel Gaddour*
- 15:25-15:45 Q&A, Panel Discussion (Regional Perspectives Panel)
- 16:00- 18:30 Research seminar small group meeting
- 19:00 – 21:00 Gala Dinner (Invitation / Ticket)

**Day 3: Saturday April 1st, 2017**

- 8:00 - 9:00 Research seminar small group meeting (breakfast meeting)
- 8:30 – 9:00 Registration
- 9:00 – 09:30 Principles in the treatment of Autism Spectrum Disorder  
*Bennett Leventhal*
- 09:30 – 10:00 Early intervention for ASD in the preschool period: An Australian experience using a community model  
*Valsamma Eapen*
- 10:00 - 10:15 Q & A and Panel Discussion
- 10:15 – 10:45 Coffee Break/Networking
- 10:45 - 11:10 Genomics of Autism: Latest advances and future directions  
*Mohammed Uddin*
- 11:10 -11:30 Research methodology and study design  
*John Fayyad*
- 11:30 – 11:50 Research and scholarship: Just do it!  
Writing and publishing scientific papers  
*Hesham Hamoda*
- 11:50 – 12:00 Q & A and Panel Discussion
- 12:00 - 1:30 Prayer and Lunch Break
- 1:30-15:30 Research Fellows Presentations  
Presentations by EMACAPAP research fellows
- 15:30 – 16:00 Closing Ceremony
- Research Awards
- Certificate Distribution
- Closing remarks and recommendations
- Group Photo
- Post Conference Program (April 2nd, 2017) — Al Jalila Children's Specialty Hospital

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## APPENDIX 4. NETWORKING RESOURCES FOR ASD PROVIDERS AND PARTICIPANTS

- ASA (Autism Society of America): [www.autism-society.org](http://www.autism-society.org)
- Autism Speaks: [www.autismspeaks.org](http://www.autismspeaks.org)
- Organization for Autism Research (OAR): [www.researchautism.org](http://www.researchautism.org)
- Interactive Autism Network (IAN): [www.ianproject.org](http://www.ianproject.org)
- Autism Science Foundation: [www.autismsciencefoundation.org](http://www.autismsciencefoundation.org)
- Simons Foundation Autism Research Initiative: [www.sfari.org](http://www.sfari.org)
- American Association on Intellectual and Developmental Disabilities (previously AAMR): [www.aaid.org](http://www.aaid.org)
- National Association for the Dually Diagnosed (NADD): [www.thenadd.org](http://www.thenadd.org)
- The ARC: [www.thearc.org](http://www.thearc.org)
- American Academy of Child and Adolescent Psychiatry (AACAP): [www.aacap.org](http://www.aacap.org)
- National Alliance on Mental Illness (NAMI): [www.nami.org](http://www.nami.org)

## APPENDIX 5. GENERAL ASD RESOURCES

An up-to-date review of the current view of ASD genetics and how genes relate to the developmental neurobiology likely to be the causal pathway for the ASD and related neurodevelopmental disorders:

- Willsey, AJ. & State, MD. Autism Spectrum Disorders: From Genes to Neurobiology. *Current Opinion in Neurobiology* (2015); 30:92-99
- A review of the current genetic risks for ASD and the rare variant approach for studying genetic etiology of developmental disorders:
- Sanders, SJ et al. Insights into Autism Spectrum Disorder Genomic Architecture and Biology from 71 Risk Loci. *Neuron* (2015) 87:6:1215-1233.
- A review of how genetic substrates for ASD may interact with environmental factor to form the etiologic substrate of ASD and related neurodevelopmental disorders:
- Kim, YS & Leventhal, BL. Genetic Epidemiology and Insights into Interactive Genetic and Environmental Effects in Autism Spectrum Disorder. *Biological Psychiatry*. 2014;77:66-74 .
- The latest CDC ASD prevalence estimates and particular attention to methods in determining prevalence:
- Zablotsky et al, Estimated Prevalence of Autism and other Developmental Disabilities Following Questionnaire Changes in the 2014 National Health Interview Survey. *National Health Statistics Reports* (2015).87:1-20
- A very well-organized, well-referenced and methodical approach to understanding the causes and treatments of ID:
- Harris, JC. *Intellectual Disability: Understanding its Development, Causes, Classification, Evaluation and Treatment*. (2006). Oxford University Press. NY
- An up-to-date, conceptual and practical framework for understanding the etiology, diagnosis, and treatment of ASD:
- Le Couteur, A and Szatmari, P. Autism Spectrum Disorder in Rutter's *Child and Adolescent Psychiatry*, 6th Edition. 2015. Thapar A, Pine DS, Leckman JF, Scott S, Snowling MJ and Taylor, EA, eds. Wiley, NY pp 665-682.



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ISBN-10: 1-944302-02-6  
ISBN-13: 978-1-944302-02-3