Perspective

A Medical Neighborhood Model for Chronic Autism Care: A Compassionate Systems Perspective

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Abstract

Children with Autism Spectrum Disorder (ASD) are four times more likely to have unmet healthcare needs compared to their neurotypical peers. This underscores the urgent need to address healthcare disparities and improve access to services. However, primary care physicians express concern about their ability to adequately serve patients with ASD and their families, indicating a potential capacity issue in the current healthcare system. Additionally, specialists such as neurologists and psychiatrists acknowledge difficulties in addressing the secondary conditions associated with ASD. The knowledge gap within the medical community and overarching health services system has resulted in barriers to treatment and disparities in healthcare access for children with ASD. Accordingly, this commentary aims to emphasize that ASD is a complex, multidimensional, multifactorial, and enduring condition requiring comprehensive and integrated services. Moreover, we submit that beyond compassionate interactions within individual relationships, what is essential for families with children with ASD are compulsory, skilled, and responsive systems of care. In this article, we present a novel, interconnected ecosystem for chronic care based on a medical neighborhood model comprised of four integral components. These components include (1) comprehensive assessment and care planning, aiming to develop individualized, holistic care plans derived from extensive patient evaluations; (2) care navigation and coordination, which employs a dedicated coordinator to facilitate communication among healthcare providers and resources; (3) anticipatory guidance, intended to empower patients towards active self-management and early intervention for potential complications; and finally, (4) technology-enabled clinical decision support and humanistic artificial intelligence systems, to provide evidence-based recommendations and personalized, empathetic patient plans of care. These four components synergistically operate to promote patient-centered care, enhancing outcomes and the overall quality of care. This commentary concludes with an outline of the requisite metrics for evaluating the impact of the proposed model of care and a payment structure to produce a high-performing healthcare system for children with ASD and their families.

Keywords: Autism spectrum disorder; Comorbidity; Medical neighborhood; Medical home; Health disparities

Introduction

Eliminating health disparities for individuals with autism spectrum disorder is a goal that has received social support; however, designing the necessary systems, protocols, and guidelines to facilitate significant transformation continues to be an ethical obligation. In the context of public health and social science, the term "disparity" has been defined as a preventable difference in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations [1]. Karpur et al. [2] citing data from the 2016 National Survey of Children's Health, confirmed that children with ASD are four times more likely to have unmet healthcare needs compared to their neurotypical peers. Health disparities among children with ASD take the form of limited availability of, and access to, essential medical and healthcare services [3]. Further, if a child belongs to an underrepresented group or a family with an income below the federal poverty threshold, health disparities are even more pronounced. Specifically, children with ASD in an underrepresented or low-income category are diagnosed later than white and more advantaged children [4], receive reduced and lower-quality care [5], and wait longer for behavioral health and medical services [6].

The Impact of Health Disparities

The ramifications of inaccessible, inadequate, and substandard healthcare are magnified for children with ASD. Specifically, children with ASD and related disorders are at disproportionate risk for adverse health outcomes due to the high prevalence of secondary conditions. Data from the 2007 National Survey of Children with Special Health Care Needs confirm that 66% of children with ASD have four or more comorbidities. In contrast, 13% of children without ASD who have special healthcare needs have as many secondary conditions [7].

The common medical comorbidities among the ASD population include epilepsy, sleep disorders, gastrointestinal disorders, metabolic disorders, hormonal dysfunction, osteoporosis, obesity, otitis media, hearing impairment, bladder and renal disorders, hypertension, diabetes, recurrent headaches and migraines, oral diseases (e.g., dental caries), immune disorders, and bacterial and viral illnesses [8]. Psychiatric disorders are also prevalent among children with ASD. In fact, Rosen et al. [9] have reported that 70% to 72% of children with ASD have at least one co-occurring psychiatric condition, the most common being anxiety and mood disorders, obsessive-compulsive disorder, attention deficit hyperactivity disorder, and oppositional defiant disorder. These comorbid conditions are correlated with increased use of pharmacology [10], increased healthcare utilization [11], and the termination of ASD therapeutic services [12]. The principal cause of treatment discontinuation (e.g., applied behavior analysis services) is familial stress [13]. In general, compared to neurotypical children, individuals with ASD present with accelerated healthcare and mental health needs [14], elevated healthcare costs [15], more hospitalizations, lower quality of life [16], and reduced life expectancy [3,17].

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Clearly, the families of children with ASD have been affected by the hardships associated with inadequate healthcare. Consequently, the critical inquiry to address is as follows: how can we rectify and reform an inherently unjust system? We submit that the solution begins with a commitment to a chronic care model and a clear understanding of the barriers to health equality.

This paper addresses several areas relevant to the improvement of a service model for ASD. Within the first section of this commentary, we outline the need for a chronic care model. Next, we describe three prominent barriers to healthcare services (i.e., the imbalance of physician supply and patient demand, physician knowledge, and the logistics of patient care) that must be addressed. We then present a medical neighborhood model of care for families with a child with ASD that includes comprehensive assessment and care planning, care navigation and coordination, anticipatory guidance, and a technology-enabled Clinical Decision Support System (CDSS) and humanistic artificial intelligence to guide effective treatment. Finally, we discuss the metrics to evaluate the efficacy of a medical neighborhood model and the funding structure required to support the model.

Chronic Care Model for ASD

Since ASD is a long-term, complex, and multifactorial condition, a chronic care model that unites an affected child, their family, providers, and the service system is necessary. A comprehensive and integrated healthcare strategy is needed that includes a credible model of care. A model of care that offers comprehensive assessment and care planning, care navigation and coordination, anticipatory guidance, and technology-enabled systems to address child development, health, and quality of life of children with ASD is required. We assert that healthcare services for children with ASD should be commensurate with those offered to their neurotypical peers. Specifically, children with ASD require the expeditious identification of primary and secondary conditions and clinical pathways developed to address co-occurring conditions. The overarching goal of services is to optimize a child's capability, comfort, and sense of calmness while enabling them to receive the benefits of therapeutic interventions their families elect to access. Fundamentally, healthcare access and high-quality care are Social Determinants of Health (SDOH). More to the point, a child's medical and psychiatric stability is a prerequisite to accessing quality therapeutic services. The absence of high-quality healthcare will affect the outcomes of therapeutic interventions. Categorically, the omission of an integrated model of care that addresses the core deficits of ASD, child development, secondary conditions, and social determinants of health will ultimately result in services that are ineffective, inconsistent, and improvident.

Understanding the barriers to accessing healthcare across the lifespans of autistic individuals is critical to ensuring the best use of healthcare resources.

The Imbalance of physician supply and ASD demand

The United States' physician workforce for ASD patients includes 8,300 child and adolescent psychiatrists [18], 1,290 pediatric neurologists [19], and 800 developmental-behavioral pediatricians [20]. These specialty providers care for over 1.2 million ASD patients under 21 years old. Given the limited number of specialists available to serve children with ASD and their families, the role of Primary Care Physicians (PCPs) is critically important. In fact, the Interagency Autism Coordinating Committee (IACC), a federal committee that coordinates federal efforts and advises the secretary of health

and human services on issues related to ASD, has emphasized the importance of primary care physicians due to the imbalance of the specialist supply and the demand for ASD services. A PCP serves as a family's "first contact" medical doctor. Therefore, the PCP's preparedness to diagnose and treat ASD is essential. Although the importance of primary care is inarguable, the barriers to the provision of appropriate services must be acknowledged. The obstacles that PCPs face, such as knowledge management and the logistics of patient care, require due consideration.

Physician knowledge

As previously indicated, children with ASD are four times more likely to face barriers to healthcare services. Access to healthcare is generally predicated on five central elements: affordability, accommodation, availability, accessibility, and acceptability [21]. Kullgren et al. [22] defined the latter element, acceptability, as the relationship between expectations for medical professionals, the contexts in which they work, and their actual characteristics as physicians. A crucial element of acceptability is the management of a knowledge infrastructure, which Davenport succinctly defines as the procedure of acquiring, disseminating, and efficiently utilizing knowledge [23]. While families naturally hope their Primary Care Providers (PCPs) would possess a deep understanding of ASD, and have access to a knowledge infrastructure, it is evident that many physicians may not yet have the necessary exposure, expertise, experience, or preparedness required to effectively address the unique needs of individuals with ASD. Yerramsetti [24] highlighted PCPs' lack of confidence in their knowledge of severe ASD symptoms. Furthermore, in a comprehensive systematic review examining primary care physicians' understanding of ASD, McCormack et al. [25] presented the findings derived from a survey completed by 2,706 primary care practitioners. Out of all completed surveys, 40.6% of responses were submitted by pediatricians, 39.8% by general practitioners, and 19.6% by unspecified sources. Only 23.1% of the physicians surveyed claimed to have adequate knowledge of ASD, while 69.2% reported inadequate knowledge. Another 7.7% of physicians were equivocal in their responses. The study also disclosed false beliefs about the defining characteristics of ASD.

Specifically, some physicians believed ASD was synonymous with intellectual and developmental disabilities, and others considered ASD to be a form of psychosis or believed it was a precursor to schizophrenia. There have been initiatives for addressing PCP knowledge gaps, such as the Autism Healthcare Accommodations Tool (AHAT) described by Nicolaidis et al. [26], the ECHO technology-enabled mentorship project [27], and the more comprehensive systematic network of autism primary care model [18], which is intended to ensure coordinated care. However, despite commendable educational initiatives, autistic people and their families continue to suffer the consequences of an infelicitous system.

Logistics of patient care

Physicians also struggle with the logistics centered on patient care and the management of relevant knowledge related to ASD. By way of illustration, Yerramsetti [24] reported themes centered on barriers to treatment. According to Yerramsetti [24], physicians report difficulties accommodating a child with ASD in their clinics. This is especially true if a child is dysregulated while waiting for an appointment and during the examination process. The implication here is that if a child is unavailable for an examination due to dysregulation, then the information acquired by a physician may be

sparse and incomplete. Consequently, a physician's recommendations may be guided by representativeness heuristics rather than specific patient factors acquired *via* a thorough exam and test results. Since a physician's ASD patient panel may be small, their personal experience may be perfunctory, and their medical management decisions may be compromised due to an insufficient experiential background. These circumstances result in a risk of substandard care. Yerramsetti [24] also identified a significant contributing factor that could impact physicians: the heightened stress experienced by physicians when managing patients who, from their perspective, may have limited potential for improvement. The perception of a limited likelihood of progress is exacerbated by a child's atypical communication and interpersonal relationships, both factors that are critical to effective healthcare interactions. Moreover, because of the child's atypical presentation and many physicians' inability to accommodate sensory challenges [28], appropriate medical services are unintentionally delayed until a condition is advanced and necessitates urgent medical intervention. Delays in medical intervention (e.g., postponement of treating functional constipation) lead to distress, anxiety, and adverse childhood experiences, which then set a precedent for protracted resistance to medical attention. In fact, a physician's inability to properly identify and diagnose a secondary condition may be responsible for the discrepancy between the prevalence of medical and psychiatric comorbidities in the professional literature and the actual claims data reported by insurance companies.

The solution

Part of the solution to the systemic barriers to proper healthcare for children with ASD is a medical neighborhood model of care wherein PCPs receive wraparound support and benefit from aggregated and curated information from an interprofessional team of experts such as speech and language pathologists, occupational therapists, physical therapists, orientation and mobility specialists, board-certified behavior analysts, and public or private school educators.

Therapy staff are in an optimal position to provide wraparound support to a PCP, since their contact with a client (e.g., often daily contact) far exceeds that of the PCP.

The Medical Neighborhood Model of Care

According to the Agency for Healthcare Research and Quality, a successful medical neighborhood focuses on meeting the individual patient's needs but also incorporates aspects of population health and community health needs. The medical neighborhood is defined as a clinical-community partnership that includes the medical and social support necessary to enhance health, with the PCP serving as the patient's central "hub" and coordinator of healthcare delivery. The implementation of the medical neighborhood model is essential in addressing the current fragmentation of services and the multitude of providers involved in patient care. The primary objectives of an effective medical neighborhood model encompass: (1) fostering collaboration among diverse medical stakeholders to facilitate seamless information exchange between clinicians and patients; (2) incorporating specialists, hospitals, home health services, long-term care facilities, and other clinical providers in the comprehensive care of patients; and (3) engaging non-clinical partners, such a community centers, faith-based organizations, educational institutions, employers, and public health agencies, in the holistic care of patients. The medical neighborhood model of care is especially well-suited for children with ASD due to the diverse range of services required, including but not limited to primary care, dentistry, speech and language therapy,

occupational therapy, physical therapy, orientation and mobility, applied behavior analysis, and various medical specialty services such as gastroenterology, neurology, and developmental pediatrics. Mental health services and

Psychiatry also plays a crucial role. Considering this, we propose that the medical neighborhood model of care be adopted as an expanded family-centered care model, fostering collaboration among Primary Care Providers (PCPs), specialty providers, speech and language pathologists, occupational therapists, physical therapists, mental health providers, educators, and board-certified behavior analysts. By working together in partnership, these stakeholders can provide comprehensive and coordinated chronic care to children with ASD and their families. The concept of the "neighbors" within the medical neighborhood structure extends beyond healthcare providers to encompass a broad spectrum of entities, including community and social service organizations, state social service agencies, and public health agencies. Effective implementation of the medical neighborhood model of care necessitates the establishment of suitable systems and processes to ensure streamlined care coordination for every patient. Given the intricate nature of care required for children with ASD, adopting a medical neighborhood model of care represents a logical and comprehensive approach. Furthermore, the success of this model relies on leveraging implementation science and disseminating knowledge to empower the healthcare system effectively. By integrating evidence-based practices and promoting continuous learning, the medical neighborhood model of care holds the potential to enhance outcomes for children with ASD and their families while ensuring optimal coordination among various healthcare and community stakeholders.

Toward the future of a medical neighborhood for ASD: A systems approach

The four key elements of a medical neighborhood that support the organizational design and management of the model are (1) comprehensive assessment and care planning, (2) care navigation and care coordination, (3) anticipatory guidance and coproduction, and (4) Clinical Decision Support Systems (CDSS) and humanistic artificial intelligence. Additionally, the model needs to be supported by a minimum clinical data set of predetermined outcome measures and a payment structure that will incentivize principled provider behavior. In essence, an ecosystem is necessary for service provision.

A structured interdisciplinary assessment framework

Developing a holistic care plan for individuals with ASD is a multi-step process that depends on the compilation and amalgamation of information derived from assessments carried out by each member of an interdisciplinary team. The members of a structured interdisciplinary assessment team include caregivers, a speech and language pathologist, an occupational therapist, a board-certified behavior analyst, and a physician, along with various adjunct professionals, depending on a child's unique needs (e.g., an orientation and mobility specialist, assistive technology specialist, vision specialist, or audiologist). Since assessments are conducted to identify a child's strengths and deficits, the assessments must be performed in concert. Each professional on the team should select the assessment tool that will provide the most accurate information regarding a child's present level of functioning for the purpose of treatment planning. Within the context of a series of interdisciplinary team meetings during the assessment process, the team should consider its observations of the child across disciplines and environments. Assessments ought to be

perceived not as a series of discrete reports generated by individual team members in isolation, but rather as a collective effort to gather data and integrate information, ultimately contributing to a more substantial and meaningful interdisciplinary outcome. With the data gathered by each professional, the team can develop goals, objectives, and a care plan that reasonably match a child's predicted pace of achievement and development. A working model for this assessment process is the Comprehensive Multi-Disciplinary Assessment Protocol for Autism Spectrum Disorder [29]. Upon completion of the assessment process, it is crucial to thoroughly document both the clinical pathways and the standard operating procedures. Clinical pathways, encompassing care maps and plans, necessitate effective, person-centered communication tools, ideally facilitated by technology, for their successful implementation. These tools should be easily accessible and uniformly employed by all members of an interdisciplinary team, serving to enhance rather than disrupt daily workflows. An essential characteristic of these clinical pathways is that they must be centered on the child's needs and deeply rooted in evidence-based practices. Furthermore, they should provide a clear depiction of the expected outcomes that both the child and the family are projected to achieve during the treatment, thus providing a measurable and attainable roadmap to success. Once the assessment process and clinical pathway are completed, the team can debrief the care navigator to enable family navigation and care coordination.

Care Navigation

Care navigation is a case management strategy that helps families navigates the healthcare system and barriers to care. Care navigation has a strong evidence base in chronic care conditions, such as oncology. The care navigator is equipped with aggregated and curated information (e.g., information specific to a catchment area) that allows the professional to answer the following questions:

- Who are the reputable providers available for referrals within a specific catchment area (e.g., neurologists, gastroenterologists, PCPs, speech and language pathologists, occupational therapists)?

- What facilities are clients likely to use that are near their home (e.g., emergency rooms, psychiatric hospitals)?

- What resources are available to address behavioral health needs and social health needs?

- What resources are available to address social determinants of health (e.g., housing, education, employment)?

The goal of care navigation is to create information symmetry. More to the point, a family should not be disadvantaged due to a lack of information or incomplete information (i.e., information asymmetry). Instead, the knowledge held by a family should align with the necessary information about a given subject, such a child's entitlement to mental health services.

One common occurrence of information asymmetry that affects families' access to proper healthcare services is centered on affordability barriers. Coombs et al. [30] found that issues affording healthcare and unanticipated medical bills were among the most prevalent barriers to healthcare access, and mental health challenges were more likely to exist when people reported barriers to healthcare access. Therefore, the link between mental health challenges and affording healthcare services for those challenges is an important area to focus on in creating information symmetry for families of children

with ASD.

Health insurance benefits are perhaps the most important mechanism to allow families to access medically necessary healthcare services. Unfortunately, many individuals with ASD are not able to access medically necessary and recommended healthcare services due to inappropriate denials of mental health benefits offered by health plans. Instances in which individuals with ASD and their families are inappropriately denied these services are generally referred to as mental health parity violations. The two statutes that are most relevant to mental health parity violations are the Mental Health Parity and Addiction Equity Act (MHPAEA) of 2008 and the Patient Protection and Affordable Care Act (ACA) of 2010, which together guarantee mental health and substance use disorder (MH/SUD) benefit coverage for most health plans. Specifically, the ACA requires that all individual and small group health plans cover MH/SUD services as one of 10 essential health benefits. It is worth noting that the ACA does not require that large group health plans cover MH/SUD benefits; however, most large group health plans do carry those benefits in addition to medical/surgical benefits. When a health plan does offer both medical/surgical and MH/SUD, the MHPAEA mandates that MH/SUD coverage be no more restrictive than any financial requirements or treatment limitations applied substantially to all medical/surgical benefits.

Although both statutes generally require that most health plans provide MH/SUD benefits to their beneficiaries, denials often occur. While these denials are appealed and sometimes lead to large class action lawsuits, resulting in compensatory damages for the represented plaintiffs (e.g., Walsh v. United Behavioral Health), many families who are wrongfully denied coverage do not ever receive the benefits to which they are entitled. As mentioned above, care navigation services can be a vital part of an effective case management strategy for ensuring families can access resources such as MH/SUD benefits, including behavioral health services for ASD.

The care navigation system is a critical component of treatment that will help a client overcome system- and individual-level barriers to quality care. The system can be enhanced using a self-tracking structure. One example of a self-tracking system is the pediatric developmental passport program [31], designed for families with a child diagnosed with ASD. The system provides a family with a structure for documenting the achievement of recommended ASD services (e.g., barium swallow study, esophageal motility study, electroencephalogram, polysomnography). Self-tracking tools such as the pediatric developmental passport aid a family's efforts to stay organized, track progress, and share information with healthcare providers. The care navigator will also facilitate care coordination among the interprofessional team.

Care coordination

Care coordination is a practice used to ensure that a client and their family receive the services they need from other providers in the medical neighborhood. The provider could be within the healthcare system (e.g., a neurologist) or outside it (e.g., at a veteran employment center). The goal of care coordination is to ensure that information is shared with other providers. Effective care coordination includes:

- Establishing systems for communication between providers and facilities.

- Allocating responsibility for care coordination, client

engagement, and ensuring the completion of referrals to medical professionals, therapy providers, and community service agencies.

- Creating well-defined workflows that have a high degree of reliability, so the client remains engaged and neither they nor their information are overlooked.

The success of care navigation and coordination hinges on the care navigator's ability to anticipate a family's needs and prevent adversity. This can be accomplished through anticipatory guidance. The exemplary care coordinator will offer proactive guidance, promote patient engagement, and foster collaborative problem-solving with the patient.

Anticipatory guidance and coproduction

Anticipatory guidance (or clinical guidance) is the advice professionals provide to avoid problems that could occur in the future. Coproduction in healthcare means that patients contribute to the provision of health services as partners of interprofessional providers.

Anticipatory guidance is a common educational practice that seeks to proactively prepare families for what they should expect in the future and how to meet the child's needs at their current and subsequent treatment stages. Anticipatory guidance needs to be prioritized for the conditions with a high probability of occurrence in children with ASD, such as sleep problems, feeding disorders, dietary challenges, bowel and bladder incontinence, and behavioral dysregulation. Anticipatory guidance can be considered as one part of the preventive care strategy framework. Preventive care strategies can be defined as strategies aimed at reducing the risk of disease or condition onset, as well as any downstream complications from a manifested disease or condition [32]. In the United States, several organizations make preventive recommendations, including the United States Preventive Services Task Force (USPSTF) and the Centers for Disease Control (CDC). There are also specialty organizations that have made more specific prevention recommendations, including the American Cancer Society (ACS) and Autism Speaks.

Traditionally, the literature has discussed three preventive stages: primary, secondary, and tertiary prevention. Each level of prevention will be discussed below, and examples of preventive care in the context of ASD will be given.

Primary prevention consists of measures aimed at a susceptible population or individual to prevent a disease or condition from ever occurring. Examples pertaining to ASD include anticipatory guidance given by healthcare professionals focused on young children's sleep patterns. Children with ASD suffer from irregular sleep-wake patterns at a higher rate than neurotypical peers. Specifically, 40% to 80% of children with ASD experience sleep problems [33]. Since there are seven categories of pediatric sleep disorders [34], anticipatory guidance is particularly important, not only for early detection, but also to prevent the occurrence of treatment in the absence of proper assessment. Anticipatory guidance related to sleep disturbances could be accomplished using actigraphy [35], an objective and non-intrusive method for evaluating sleep-wake patterns. Actigraphy provides an objective measure of activity and moves the assessment process away from parental self-report. Actigraphy can be used to detect and react to any "red flags" that, if left unaddressed, will evolve into a more serious problem. Secondary prevention consists of measures aimed at early symptom detection in individuals with subclinical or early-

stage symptoms of a disease or condition. Examples pertaining to ASD include early identification of symptoms related to a feeding or eating disorder, such as difficulty accepting solid foods or slow eating patterns [36]. Tertiary prevention consists of measures aimed at reducing the severity of a disease or condition that has been established in an individual and preventing further progression of that disease or condition. These include addressing dietary challenges, such as limited food repertoire and high-frequency single-food consumption [37].

More recently, two additional stages have been included in the preventive stage literature: primordial prevention and quaternary prevention [32]. Primordial prevention consists of measures aimed at reducing disease risk factors in an entire population through a focus on social and environmental conditions. An example of primordial prevention would be preventing and reducing childhood obesity in children with ASD to prevent chronic diseases such as hypertension and diabetes later in life. Quaternary prevention consists of measures aimed at protecting individuals from medical interventions that are likely to cause more harm than good. Examples pertaining to ASD include coordinating with providers to ensure co-occurring therapies are not contraindicated or educating caregivers to recognize and understand the components and benefits of using evidence-based interventions to help advocate for effective treatments.

Given its classification as a primary preventive measure, anticipatory guidance has the potential to be an integral part of achieving the predetermined key outcomes of a medical neighborhood model of care. The National Institute of Health (NIH) Office of Disease Prevention (ODP) recently published a review of the NIH prevention research portfolio for Fiscal Years (FY) 2012-2019 [38]. In that review, the researchers estimated that 20.7% of NIH research projects in FY 2019 were focused on primary and secondary prevention research in humans, an increase from 17.6% of projects in FY 2012. Most notably for the purposes of this paper, the study classified an estimated 11.8% of projects as motivated by mental health and 7.6% of projects as having a dependent variable related to mental health. Those two estimations were ranked seventh and sixth, respectively, in an overall listing of project rationales and outcomes. The results suggested that mental health remains a smaller focus of NIH prevention research compared to other study motivational rationales (e.g., mortality, infectious diseases) and dependent variables (e.g., cancer). Studies have suggested that parents report unmet needs to pediatric providers for guidance related to child development, discipline, and safety [39]. Proper anticipatory guidance from medical providers can help meet those needs for parents.

Anticipatory guidance has been shown to be effective at decreasing maternal stress, encouraging desired proactive parenting behaviors, and eliminating undesired parenting behaviors for mothers of young children across various ethnic and racial backgrounds [40]. Given the demonstrated efficacy of anticipatory guidance across different populations, more research needs to be conducted to help remove barriers to anticipatory guidance provision by providers (e.g., lack of time, training, and knowledge management systems) and identify the variables that affect the efficacy of anticipatory guidance for specific families. It should be noted that anticipatory guidance should also be used for clinical teams (i.e., teams should be the beneficiaries of anticipatory guidance delivered by a subject matter expert).

An understanding of the specific supports and services a child will require (i.e., due to a primary or secondary condition) enables a team

to prepare appropriately and ensure it is working within its scope of competence and practice. One variable that should be considered and could play an important mediating role in a medical neighborhood model of care is health literacy.

The role of health literacy and family training in anticipatory guidance efficacy and care navigation

Health literacy can be defined as the degree to which individuals can obtain, process, and understand basic health information and services needed to make appropriate health decisions. It has been deemed a key safety and quality issue by the CDC, the Joint Commission, and the American Academy of Pediatrics [41]. Based on that definition, health literacy can be considered an integral part of providing effective anticipatory guidance to parents and caregivers of children with ASD in a medical neighborhood model of care. If a parent or caregiver cannot understand physician guidance and engage in key recommended healthcare behaviors (i.e., possesses a low level of health literacy), there is a low likelihood that anticipatory guidance will have its intended effect. Additionally, the latest literature on health literacy reflects a movement toward a bidirectional framework regarding health literacy. That is, by nature, health literacy issues include not only an individual's capacity to make appropriate health decisions but also the ability of the individual's healthcare system to meet its patients' and families' needs.

Both care navigation and anticipatory guidance can be enabled by technology, such as a clinical decision support systems and humanistic artificial intelligence.

Clinical decision support systems and humanistic artificial intelligence

The Health Information Technology for Economic and Clinical Health (HITECH) Act, under the American Recovery and Reinvestment Act of 2009, was initiated to stimulate the development and application of information technology within the healthcare system. The goal of the HITECH Act is to achieve the meaningful use of Electronic Health Record (EHR) systems throughout the nation. According to the CDC [1], the central goals of meaningful use include:

1. Improving quality, safety, and efficiency and reducing health disparities.

2. Engaging patients and families in their health.

3. Improving care coordination.

4. Improving population and public health.

5. Ensuring adequate privacy and security protection for personal health information.

The HITECH Act allotted $22.6 billion to promote the implementation of information systems and Clinical Decision Support Systems (CDSSs) to be used within the healthcare setting [1]. Yet, the crucial inquiry remains: How significantly have the lives of children with ASD and their families been impacted by the substantial $22.6 billion investment? One potential avenue for benefitting children is through the utilization of ASD-specific technology-enabled Clinical Decision Support Systems (CDSS) and humanistic artificial intelligence. A CDSS is a type of software that interprets specific patient information that is entered into the system to aid in making the most appropriate and safe decisions when providing patient care. A CDSS takes the data and information entered and processes it with the assistance of specific organizational models, algorithms,

and calculations to achieve a variety of potential action steps based on a patient's unique profile. The information a CDSS gathers about a specific patient is subject to prompts, alerts, and recommendations delivered to the end user in real time. A CDSS does not supplant clinical judgment; rather, the technology serves as a knowledge management tool and a serviceable supplement to a provider's clinical repertoire and clinical judgment. A CDSS can take a variety of forms: (1) the CDSS could be a generic and commercially available structure used by a provider (e.g., a PCP); (2) the CDSS could be a system developed for a provider through a user experience design (UX-D) and User Interface (UI) process resulting in customized components; or (3) the CDSS could be a system that is custom-built for a provider. Clinical decision support systems can either be active or passive. An active CDSS presents information to a clinician that is retrieved by comparing available patient information with the programmed rules, protocols, and guidelines by using a knowledge infrastructure, available patient information, and an inference engine (i.e., expert system). A knowledge database includes organizational protocols, guidelines, and rules developed using evidence-based research and ethical compliance codes. Available patient information includes data retrieved from direct and indirect observations and data entered by clinicians. The inference engine compares the available patient information with the knowledge base to deliver pertinent information to the end user. Active CDSSs deliver information with the immediate presentation of alerts and suggestions regarding an appropriate clinical pathway for the patient. A passive CDSS presents additional available resources for the clinician to access through a link if further information is desired. A CDSS can equip a provider with physician protocols (e.g., best practices for managing functional constipation). An example of a passive system would be the Cochrane Database of Systematic Reviews (CDSR), which is the leading journal database for systematic reviews in healthcare. The CDSR includes systematic reviews, protocols, commentary, and serviceable supplements. The autism service industry requires a comparable structure. A CDSS is the main tool that enables effective care navigation, care coordination, and the operationalization of clinical services. Indeed, in the current era, we are contending with an obsolescent paradigm of knowledge management. Frequently, the well-being of patients, along with the hope of their families, is precariously balanced upon the solitary expertise of an individual healthcare practitioner. This situation calls for a transformative shift. The extensive compendium of medical and clinical knowledge should be readily accessible to healthcare providers and families seeking support. The establishment of such an expansive and all-inclusive support system requires a fusion of cutting-edge technology and an intricately organized knowledge infrastructure, augmented by artificial intelligence with an emphasis on humanistic principles.

Although a CDSS and Humanistic AI are crucial, we also propose that assessing the effectiveness of a medical neighborhood model of care necessitates the implementation of a multifaceted approach.

Measuring the impact: a multimethod approach

An array of measures is required to evaluate the impact of a model such as the medical neighborhood model for ASD and outcomes for children with ASD (e.g., health outcomes, clinical outcomes, and the cost-effectiveness of services). Specifically, there need to be measures to evaluate (1) the efficacy of the systems (e.g., the medical neighborhood model, care navigation, care coordination, and anticipatory guidance) to support a child and their family; (2) the

impact of interdisciplinary services on the core deficits of ASD (i.e., ASD-specific measures); (3) quality of life due to the prevalence of medical and psychiatric comorbidities; and (4) the cost-effectiveness of services.

Areas of Assessment

Care Navigation and Care Coordination Accountability Measures The purpose of a medical neighborhood model is to improve communication and coordination between the various neighbors in the medical neighborhood. In the case of ASD services, the "neighbors" include speech and language pathologists, occupational therapists, physical therapists, orientation and mobility specialists, board-certified behavior analysts, primary care physicians, medical specialists, mental health providers, and psychiatrists. The primary goal of such a model is to facilitate the flow of information across providers and patients to ensure that all stakeholders have a broad understanding of a patient's needs so care can be coordinated effectively. To evaluate this goal's fulfillment, we recognize the need for measures to evaluate the efficacy of the medical neighborhood model, care navigation, care coordination, and anticipatory guidance. The Care Coordination Measures Atlas [42], is a particularly valuable resource. The Atlas is a compendium of 61 instruments for measuring care navigation and care coordination. One instrument that can be used to evaluate the efficacy of the medical neighborhood model is the Family-Centered Care Self-Assessment Tool-Family Version. The assessment tool allows a provider to survey parents or caregivers about the provision of family-centered pediatric services. Ninety of the 98 assessment items relate to care navigation, care coordination, and anticipatory guidance. Besides determining whether the overall system is impacting the family, it is also important to determine whether clinical and medical services are having the desired effect at the individual level.

Advances in assessment

According to Frechter et al. [43], the effects of autism treatment should be determined using a robust and standardized set of outcome measures and evaluation processes. The Behavioral Health Center of Excellence (BHCOE) offers an accreditation for ASD service providers and the BHCOE ABA Outcomes Framework for evaluating the outcomes of autism treatment. Additionally, the International Consortium for Health Outcomes Measurement (ICHOM, 2021) recently produced the Autism Spectrum Disorder Standard Set (ASDSS) based on input from leading autism researchers, psychologists, board-certified behavior analysts, and service user representatives from Europe, North and South America, and Asia. Specifically, the ASDSS suggests measuring nine outcomes: (a) restricted and repetitive behaviors, (b) social communication, (c) daily functioning, (d) leisure, (e) quality of life, (f) family functioning, (g) emotional regulation, (h) anxiety, and (i) sleep issues. The ASDSS framework provides a clear guide for evaluating treatment outcomes for families, clinicians, and payers.

Beyond the measurement of systems' efficacy, other evaluations should include ASD-specific assessments such as the Autism Diagnostic Observation Schedule (ADOS) and it's Severity Score. The ADOS is a semi-structured ASD observation measure for evaluating children and diagnosing ASDs across age spans, developmental levels, and language skills [44]. Norm-referenced assessments, such as the Vineland-III Adaptive Behavior Scales [45], are serviceable tools for evaluating adaptive functioning.

Additionally, criterion-referenced assessments, such as the Verbal Milestones Assessment and Placement Program [46] and the Promoting Emergence of Advanced Knowledge (PEAK) assessment [47], are systems designed as evaluation and curriculum guides focused on teaching language and cognitive skills to children with ASD. Many educational settings use these criterion-referenced assessments to establish appropriate language goals and objectives for individuals with ASD and other developmental disabilities. Finally, quality of life assessments, such as the Pediatric Quality of Life Inventory (Varni et al., 2001) [48], can be used to evaluate physical, emotional, social, and school functioning. However, since the goal of treatment is to effect socially significant change in a child with ASD while also maximizing the health and health effects of interventions on others impacted by services (i.e., caregiver effect and family effect), an assessment tool that measures the health-related quality of life of caregivers is also important. The health of caregivers will have both quality-of-life implications and economic benefits. A tool such as the 12-item Short-Form Health Survey can be used [49]. Allik et al. [50] measured the quality of life of parents and other caregivers of children with ASD. Finally, an assessment battery should also include tools used by speech and language pathologists, occupational therapists, physical therapists, and orientation and mobility specialists.

Additional clinical measures

Beyond the exclusive assessment of client outcomes, we propose a multi-faceted approach to gauging the efficacy of ASD-oriented constructed environments for children. This strategy encompasses several key parameters, such as calculating mean treatment durations for each client, implementing periodic proficiency assessments for all clinicians involved with the child, and enforcing procedural fidelity evaluations to ensure the consistent, rigorous implementation of evidence-based methodologies. In addition to these criteria, we advocate for integrating an appraisal of the quality of clinical documentation into the evaluation process and assessing parental satisfaction. To ensure impeccable service standards, quality assurance review scores and incident reports ought to be thoroughly inspected. Furthermore, it is crucial to scrutinize the caliber of supervision provided by Board-Certified Behavior Analysts and assess the use of recommended therapeutic dosages, colloquially referred to as authorized services. We also implore consideration of the evaluation of 'organizational health' within any community designated to serve children with ASD. Without robust organizational health, the potency of any envisaged treatment may be undermined by factors such as high staff turnover, dispirited employees, and clinical personnel who lack the necessary motivation and enthusiasm for the

support they extend to children. For a comprehensive assessment, we suggest all metrics be subjected to rigorous analytical techniques, such as Growth Value Scores, to yield quantitative measures of progress. Finally, it is vital to ensure all services are rendered within the parameters of a clearly delineated treatment philosophy, thereby establishing a consistent, informed approach to therapy.

On the philosophy of autism treatment

A well-defined treatment philosophy for autism is essential in the medical field to define and articulate the key principles and goals of effective autism treatment and guide the implementation of interventions. Developing a treatment philosophy involves collaborative discussions within a team to address critical questions, including the rationale behind the chosen treatment approach and

the underlying reasons for its selection. In the Medical Neighborhood section of this commentary, we have outlined what, in our opinion, autism treatment is and what

should be done. Therefore, the question at this juncture is this: How should autism treatment is administered? A meticulously delineated treatment doctrine is indispensable. It provides the anchoring principles, pragmatic stipulations, and encompasses a spectrum of objectives-both theoretical and applied-that shape the course of therapeutic interventions as a humanitarian enterprise.

There is a wealth of knowledge about Applied Behavior Analysis (ABA), which is a recognized basis for much of the treatment of children with ASD; however, as Trump and Ayres [51] rightfully noted in a recent publication, "nothing explicitly classifies ABA as a treatment; rather, ABA is a set of principles used to inform treatment across many different disciplines, as well as different socially significant behaviors, regardless of disability." A philosophy of treatment is, at once, necessary and a great companion of ABA, as it is to every science, because it forces all of us to ask the important questions and define the approach to treatment.

We align with the Naturalistic Developmental Behavioral Intervention (NDBI) model of treatment for many reasons: first, because the model emphasizes child engagement and instruction rooted in knowledge of child development; second, because there is an emphasis on parent-implemented intervention for addressing the core deficits of ASD (e.g., expressive language, nonverbal communication, imitation); third, because the model has an allegiance to interdisciplinary collaboration and a clear standard for human interactions; fourth, because the theoretical underpinnings of the NDBA model build upon important contributions from the work of Piaget [52], Bruner [53], and finally, because of the clear delineation of the components of effective interaction.

Turning our attention to the financial dimension of this medical framework, it is crucial to prioritize the establishment of a robust and sustainable payment structure that supports the comprehensive services associated with autism within the medical neighborhood model [54].

Payment structure

The traditional payment system for autism support services in the United States is Fee-For-Service (FFS). Within this structure, a professional (e.g., SLP, OT, board-certified behavior analyst) is compensated for each hour of service provided. The issue with the FFS payment model is twofold. First, the structure incentivizes the maximization of the therapy hours a child receives, and the billing codes used to access compensation for services [55]. The model encourages the inflation of hours for children with coveted reimbursement rates, the minimization of hours for children with unfavorable rates, and prescriptions for unnecessary treatment, since some services are associated with higher compensation-ultimately disincentivizing support that would benefit the child (i.e., coordination of care and interprofessional collaboration) due to the lack of compensation for such services. Second, the model lacks accountability within the FFS structure: There is no regard for service effectiveness, no expectations centered on outcomes, and no conjoined system that incentivizes favorable results (i.e., quality of life changes due to effective treatment) [56].

The alternative to the FFS model is a Value-Based Care (VBC)

structure for service compensation, which is more conducive to providing the type of comprehensive assessment process presented in this chapter. VBC is a service delivery framework that incentivizes providers to focus on the quality rather than the quantity (i.e., hours) of professional services delivered [57]. The VBC model is an ascendant philosophy of payment-an antidote to the prodigality of the FFS model. More to the point, a VBC structure is a sine qua non for a healthy system that will support (1) the requisite time to complete a comprehensive assessment, (2) incentives for high-quality services, and (3) the optimization of socially significant outcomes for children with ASD and their families. In short, if the proponents of the FFS structure manage the quality of ASD services, the quality of ASD services will not improve [58]. Alternatively, if a VBC system is used to support ASD service delivery, the model will enhance the quality of life of children, their families, and the interprofessional community seeking to support them.

Conclusion

Children with ASD have unmet needs due to the limited availability of supports and access to essential medical and healthcare services. Within this commentary, we have identified several barriers to equitable healthcare and outlined the constituent parts of an integrated ecosystem (i.e., a medical neighborhood model of care) to promote a high-performing system for supporting children with ASD and their families. We submit that a successful medical neighborhood model is dependent on four key elements: (1) comprehensive assessment and care planning, (2) care navigation and coordination, (3) anticipatory guidance and coproduction, and (4) a Clinical Decision Support Systems (CDSS) and humanistic AI for knowledge infrastructure. This concept of wraparound support is hardly revolutionary. For example, a collaborative care model that maximizes the impact of mental health workers has been previously described in the literature. Specifically, Katzelnick and Williams have discussed the merits of a collaborative care model and have called for the adoption of implementation science and knowledge dissemination to bring collaborative care into practice. We believe that this commentary will facilitate the progressive realization of a laudable standard (i.e., a medical neighborhood model of care for ASD). Ultimately, we passionately advocate for the creation of a compassionate "system", transcending the boundaries of compassionate "care" - which manifests as action in response to empathy within the context of relationships to encompass the entire care framework.

Indeed, it is the strategic alignment of healthcare providers, medical institutions, organizations, and resources that will fundamentally alleviate the hardship, emotional distress, and burdens experienced by children with ASD and their families. Compassion within a relationship is undeniably beneficial; however, it is an ecosystem based on compassionate "systems" that will have the greatest impact on quality of life. In our opinion, a compassionate system takes the form of a medical neighborhood model for addressing the chronic care needs of children with ASD and their families conjoined with a structured assessment process, interprofessional treatment planning, anticipatory guidance, care navigation and coordination, and the use of clinical decision support and humanistic AI for knowledge management. A compassionate system also tracks and analyzes patient-reported outcomes. Regarding outcomes, we align with Liu suggestion that three priorities that drive quality of life and dignity are capability, comfort, and calm (i.e., the three Cs). Within the proposed medical neighborhood model outlined in this article, capability is

addressed *via* the recommended assessment and intervention process, designed to improve a child and family's functional status. Comfort measures relief from physical and emotional pain. Consequently, an interdisciplinary approach involving the management of impactful co-occurring conditions has been recommended within our model. Calm measures the extent to which a child and family continue their life (e.g., self-care) during the process of treatment. Therefore, the Care Navigation system is a keystone to the medical neighborhood model. The three Cs enable clinicians to maintain focus on a child and family's progress due to effective and compassionate treatment, but also the encumbrance of suffering, the suspensions and sacrifices of life, and the stresses of coordinating and receiving proper care. To abstain from adopting this paradigm of care is tantamount to relinquishing the pursuit of establishing equitable and efficacious services for children diagnosed with ASD. Therefore, it is imperative that we take decisive action to prevent the continued stagnation and suffering faced by children with ASD and their families. Failure to do so would be a tragic condemnation, leaving them trapped in a relentless cycle of adversity. It is crucial that we unite in a determined effort to drive progress and effect meaningful change, thereby securing a brighter future for individuals and families impacted by autism spectrum disorder.

References

1. Centers for Disease Control and Prevention. CDC Health Disparities and Inequalities Report 2013. U.S. Department of Health & Human Services. CDC; 2013.

2. Karpur A, Lello A, Frazier T, Dixon PJ, Shih AJ. Health disparities among children with autism spectrum disorders: Analysis of the National Survey of Children's Health 2016. J Autism Dev Disord. 2019;49(4):1652-64.

3. Bishop-Fitzpatrick L, Kind AJ. A scoping review of health disparities in autism spectrum disorder. J Autism Dev Disord. 2017;47(11):3380-91.

4. Manning SE, Davin CA, Barfield WD, Kotelchuck M, Clements K, Diop H, et al. Early diagnoses of autism spectrum disorders in Massachusetts birth cohorts, 2001-2005. Pediatrics. 2011;127(6):1043-51.

5. Broder-Fingert S, Shui A, Pulcini CD, Kurowski D, Perrin JM. Racial and 29 ethnic differences in subspecialty service use by children with autism. Pediatrics. 2013;132(1):94-100.

6. Magaña S, Lopez K, Aguinaga A, Morton H. Access to diagnosis and treatment services among Latino children with autism spectrum disorders. Intellect Dev Disabil. 2013;51(3):141-53.

7. Bethell CD, Kogan MD, Strickland BB, Schor EL, Robertson J, Newacheck PW. A national and state profile of leading health problems and health care quality for US children: Key insurance disparities and across-state variations. Acad Pediatr. 2011;11(3 Suppl):S22-33.

8. Bauman ML. Medical comorbidities in autism: Challenges to diagnosis and treatment. Neurotherapeutics. 2010;7(3):320-7.

9. Rosen TE, Mazefsky CA, Vasa RA, Lerner MD. Co-occurring psychiatric conditions in autism spectrum disorder. Int Rev Psychiatry. 2018;30(1):40-61.

10. Mandell DS, Morales KH, Marcus SC, Stahmer AC, Doshi J, Polsky DE. Psychotropic medication uses among Medicaid-enrolled children with autism spectrum disorders. Pediatrics. 2008;121(3):e441-8.

11. Gurney JG, McPheeters ML, Davis MM. Parental report of health conditions and health care use among children with and without autism: National Survey of Children's Health. Arch Pediatr Adolesc Med. 2006;160(8):825-30.

12. Croen LA, Shankute N, Davignon M, Massolo ML, Yoshida C. Demographic and clinical characteristics associated with engagement in behavioral health treatment among children with autism spectrum disorders. J Autism Dev Disord. 2017;47(11):3347-57.

13. Kerns CM, Newschaffer CJ, Berkowitz SJ. Traumatic childhood events and autism spectrum disorder. J Autism Dev Disord. 2015;45(11):3475-86.

14. Deavenport-Saman A, Lu Y, Smith K, Yin L. Do children with autism overutilize the emergency department? Examining visit urgency and subsequent hospital admissions. Matern Child Health J. 2016;20(2):306-14.

15. Shea LL, Xie M, Turcotte P, Marcus S, Field R, Newschaffer C, et al. Brief report: Service use and associated expenditures among adolescents with autism spectrum disorder transitioning to adulthood. J Autism Dev Disord. 2018;48(9):3223-7.

16. Arias VB, Gómez LE, Morán ML, Alcedo MÁ, Monsalve A, Fontanil Y. Does quality of life differ for children with autism spectrum disorder and intellectual disability compared to peers without autism? J Autism Dev Disord. 2018;48(1):123-36.

17. Hirvikoski T, Mittendorfer-Rutz E, Boman M, Larsson H, Lichtenstein P, Bölte S. Premature mortality in autism spectrum disorder. Br J Psychiatry. 2016;208(3):232-8.

18. Kong X, Liu J, Chien T, Batalden M, Hirsh DA. A systematic network of Autism Primary Care Services (SYNAPSE): A model of coproduction for the management of autism spectrum disorder. J Autism Dev Disord. 2020;50(5):1847-53.

19. Gee AL, Gee A. Filling the gap in pediatric neurology. Practical Neurology. 2018.

20. Soares N, Baum R, Patel D. Developmental-behavioral pediatrics education in the United States: Challenges in the midst of healthcare evolution. Int J Med Educ. 2017;8:396-9.

21. Penchansky R, Thomas JW. The concept of access: definition and relationship to consumer satisfaction. Med Care. 1981;19(2):127-40.

22. Kullgren JT, McLaughlin CG, Mitra N, Armstrong K. Nonfinancial barriers and access to care for US. adults. Health Ser Res. 2012;47(1 pt 2):462-85.

23. Davenport TH. Saving its soul: Human-centered information management. Harvard Business Review. 1994.

24. Yerramsetti AP. 29.5 The other patients: Caregiver and clinician stress in treating autism spectrum disorder. J Am Acad Child Adolesc Psychiatry. 2017;56(10):S45.

25. McCormack G, Dillon AC, Healy O, Walsh C, Lydon S. Primary care physicians' knowledge of autism and evidence-based interventions for autism: A systematic review. Review J Autism Dev Disord. 2019;7(3):226-41.

26. Nicolaidis C, Raymaker D, McDonald K, Kapp S, Weiner M, Ashkenazy E, et al. The development and evaluation of an online healthcare toolkit for autistic adults and their primary care providers. J Gen Intern Med. 2016;31(10):1180-9.

27. Mazurek MO, Curran A, Burnette C, Sohl K. Echo autism stat: Accelerating early access to autism diagnosis. J Autism Dev Disord. 2018;49(1):127-37.

28. Mason D, Ingham B, Urbanowicz A, Michael C, Birtles H, Woodbury-Smith M, et al. A systematic review of what barriers and facilitators prevent and enable physical healthcare services access for autistic adults. J Autism Dev Disord. 2019;49(8):3387-400.

29. Dodd J, Franke LK, Grzesik JK, Stoskopf J. Comprehensive multi-disciplinary assessment protocol for autism spectrum disorder. J Intellect Disabil Diagn Treat. 2014;2(1):68-82.

30. Coombs NC, Meriwether WE, Caringi J, Newcomer SR. Barriers to healthcare access among U.S. adults with mental health challenges: A population-based study. SSM Popul Health. 2021;15:100847.

31. Young E, Aiyadurai R, Jegathesan T, Brown C, Bechard N, Minhas RS, et al. Increasing access to developmental services for children with autism spectrum disorder: The pediatric developmental passport pilot randomized trial. J Autism Dev Disord. 2019;49(12):4867-76.

32. Kisling LA, Das JM. Prevention Strategies. In: StatPearls. Treasure Island (FL): StatPearls Publishing; 2023.

33. Cortesi F, Giannotti F, Ivanenko A, Johnson K. Sleep in children with autistic spectrum disorder. Sleep Med. 2010;11(7):659-64.

34. Sateia MJ. International Classification of Sleep Disorders-third edition. Chest. 2014;146(5):1387-94.

35. Meltzer LJ, Montgomery-Downs HE, Insana SP, Walsh CM. Use of actigraphy for

assessment in pediatric sleep research. Sleep Med Rev. 2012;16(5):463-75.

36. Peterson K, Ibañez V. Food selectivity and autism spectrum disorder: Guidelines for assessment and treatment. TEACHING Exceptional Children. 2018;50(6):322-32.

37. Marí-Bauset S, Zazpe I, Marí-Sanchis A, Llopis-González A, Suárez-Varela MM. Anthropometric measurements and nutritional assessment in autism spectrum disorders: A systematic review. Res Autism Spectr Disord. 2015;9:130-43.

38. Murray DM, Ganoza LF, Vargas AJ, Ellis EM, Oyedele NK, Schully SD, et al. New NIH Primary and secondary prevention research during 2012-2019. Am J Prevent Med. 2021;60(6):e261-8.

39. Combs-Orme T, Holden Nixon B, Herrod HG. Anticipatory guidance and early child development: Pediatrician advice, parent behaviors, and unmet needs as reported by parents from different backgrounds. Clin Pediatr (Phila). 2011;50(8):729-37.

40. Hsu HC, Lee SY, Lai CM, Tsai WL, Chiu HT. Effects of pediatric anticipatory guidance on mothers of young children. West J Nurs Res. 2018;40(3):305-26.

41. Morrison AK, Glick A, Yin HS. Health literacy: Implications for child health. Pediatr Rev. 2019;40(6):263-77.

42. McDonald KM, Schukltz E, Albin L, Pineda N, Lonhart J, Sundaram V, et al. Care coordination measures atlas update. Agency for Healthcare Research and Quality, Rockville; 2014.

43. Frechter Y, Demirsoy I, Cameron MJ, Wirtjes P. Toward a value-based care model for children with autism spectrum disorder. Autism Spectr Disord Open Access. 2022;2(1):09-14.

44. Lord C, Rutter M, DiLavore PC, Risi S, Gotham K, Bishop S. Autism Diagnostic Observation Schedule, Second Edition. Torrence, CA: Western Psychological Services; 2012.

45. Sparrow SS, Cicchetti DV, Saulnier CA. Vineland-3: Vineland Adaptive Behavior Scales - third edition. Pearson; 2016.

46. Sundberg ML. VB-Mapp: Verbal behavior milestones assessment and placement program: A language and social skills assessment program for children with autism or other developmental disabilities. AVB Press; 2008.

47. Dixon MR. Promoting the emergence of advanced knowledge relational training system: Direct training module. Carbondale, IL: Shawnee Scientific Press LLC; 2014.

48. Varni JW, Seid M, Kurtin PS. PedsQL 4.0: Reliability and validity of the Pediatric Quality of Life Inventory™ version 4.0 Generic Core Scales in healthy and patient populations. Med Care. 2021;39(8):800-12.

49. Ware JE, Kosinski M, Keller SD. A 12-item short-form health survey. Med Care. 1996;34(3):220-33.

50. Allik H, Larsson JO, Smedje H. Health-related quality of life in parents of school-age children with Asperger syndrome or high-functioning autism. Health Qual Life Outcomes. 2006;4:1.

51. Trump CE, Ayres KM. Autism, insurance, and discrimination: The effect of an autism diagnosis on behavior-analytic services. Behav Anal Pract. 2019;13(1):282-9.

52. Piaget J. The origins of intelligence in children. New York: WW Norton & Co; 1952.

53. Bruner JS, Garton A. Learning how to do things with words. In: Human growth and development. London: Taylor & Francis Group; 1979.

54. Katzelnick DJ, Williams MD. Large-scale dissemination of collaborative care and implications for psychiatry. Psychiatr Serv. 2015;66(9):904-6.

55. Writer S. International Consortium for Health Outcomes Measurement launches the first-ever global standard set to enhance care for autism spectrum disorder. Autism Spectrum News. 2021.

56. Liu TC, Bozic KJ, Teisberg EO. Value-based healthcare: Person-centered measurement: Focusing on the Three C's. ClinOrthop Relat Res. 2017;475(2):315-7.

57. Taylor BA, LeBlanc LA, Nosik MR. Compassionate care in behavior analytic treatment: Can outcomes be enhanced by attending to relationships with caregivers? Behav Anal Pract. 2018;12(3):654-66.

58. Hanfmann E, Vakar G. Thought and language. The MIT Press; 1965.