Systems of Care for Children and Youth with Autism Spectrum Disorders

Andres J. Pumariega

Abstract

Over recent decades, significant strides have been made in evidence-based care for children with autism spectrum disorders, yet we lack a comprehensive system of care approach to address the needs of children/youth/families with ASD, including clinical, support, educational, and social needs. We have fragmented components of a system that are poorly knit together so that navigating them are too challenging for families, especially for those with less education, poorer economic resources, and families of minority children/youth who are now the numerical minority as of 2020. This chapter explores the history of systems of care for children with ASD, the current status of that system, and envisions a system that meets the diverse needs of children and families.

Keywords

Autism spectrum disorders · Autism · Systems of care · Level of care

---

A. J. Pumariega (✉)
Division of Child and Adolescent Psychiatry, Department of Psychiatry, University of Florida College of Medicine, Gainesville, FL, USA
e-mail: pumariegaa@ufl.edu

Introduction

The prevalence of autism spectrum disorders (ASD) has been increasingly adjusted upward over the last one to two decades, and it is unclear whether this is a result of increased incidence or better identification. Over the past four decades, there have been significant advancements in the assessment, treatments, and services for children and youth with ASD. These have included early systematic screening, comprehensive assessments, applied behavioral analysis, social skills training, speech and OT interventions, and adjunctive pharmacotherapy such as atypical antipsychotics for irritability and aggression and the more effective identification and management of comorbid disorders such as ADHD and anxiety disorders.

In spite of these advances, there are still major challenges in accessing care for children with ASD and their families. These services have not grown and scaled up to the level at which we now identify children, youth, and adults with ASD and emotional/behavioral needs. They are also associated with a confusing array of portals of entry and agencies for different age groups, dispersed location of services, disparate criteria for qualification for services, and divergent funding streams. These result in significant fragmentation of these services across service systems and providers. While we have experienced recent

P. McPherson (ed.), *Handbook of Treatment Planning for Children with Autism and Other Neurodevelopmental Disorders*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-031-06120-2_4

improvements in insurance coverage for services for ASD and recent inclusion in Medicaid and third-party private plans, at the same time, there has been relative defunding of special education services in public schools, which has adversely affected recently instituted and hard-won educational services for ASD. There is also unevenness of standards of care in skill and expertise in the care of ASD that diminish service effectiveness.

A growing concern is the potentially rising cost of care for people with ASD. Blaxill et al. (2021) estimated the future cost of ASD in the United States using a forecast model that accounts for the true historical increase in ASD, with inputs including ASD prevalence, census population projections, six cost categories, ten age brackets, inflation projections, and three future prevalence scenarios. They estimate that future ASD costs will increase dramatically: from total base-case costs of $223 (175–271) billion/year in 2020 to $589 billion/year in 2030, $1.36 trillion/year in 2040, and $5.54 (4.29–6.78) trillion/year by 2060. Rising prevalence, the shift from child- to adult-dominated costs, the transfer of costs from parents onto government, and the soaring total costs raise pressing policy questions and demand an urgent focus on prevention strategies, which present opportunities for savings.

This chapter outlines the trajectory of recognition of the special clinical and support needs of people with ASD and the development of services and technologies to address these needs before moving to the challenge of a fragmented service system for this population, and a possible model that might promote coherence, effectiveness, and address cost concerns.

Brief Historical Review of the Evolution of ASD Services

It is now believed that ASD have been present among humans for millennia, but it was not until relatively recently that it has been recognized as a distinct behavioral entity with specific neurodevelopmental characteristics. People with ASD were likely cared for at home, with naturalistic accommodations made by family and communities. The first documented effort at specific identification an intervention occurred around 1800 by Dr. Jean-Marc-Gaspard Itard, a French physician, who studied a boy found naked and abandoned in a forest. The boy did not speak, did not respond to language and seemed deaf, and spent his time rocking and shelling beans. Itard disagreed with the prevailing medical opinion that dismissed the boy as being an "imbecile," and he cared for the boy and experimented with compassionate behavioral approaches to help him, with his notes later published in the book titled the *Wild Boy of Aveyron* (Wolf, 2004).

For the next one- and one-half centuries, people with ASD continued to be confused and comingled with people with intellectual disabilities and served primarily in large congregate residential programs. These were either funded by state governments or charitable nonprofit entities, though largely serving well-to-do families. One example was the Massachusetts School for the Feeble-Minded, subsequently renamed the Fernald State School, founded in 1848 by Dr. Samuel Gridley Howe, a physician and anti-abolition activist who had previously had success founding a school for the blind in that state (married to Julia Ward Howe, author of the Civil War anthem, The Battle Hymn of the Republic). Interestingly, this program came about after Dr. Howe conducted a systematic survey of "idiocy" that included data from 574 people thoroughly examined by him and colleagues in 63 towns in Massachusetts. The survey, which was intended as an advocacy tool to support the need for state funded residential services, included numerous people who exhibited clear documented signs and symptoms of ASD. He also documented the deplorable living conditions of these individuals, largely adults, in almshouses, kept in cages, and left to wonder unclean and uncared for, making the ethical case for improved care and living conditions (Donvan & Zucker, 2016).

Helena Trafford Devereaux, a young Philadelphia teacher, took another route to the development of residential services originating from her experiences with disabled children underserved by the public education system. She began teaching some of these children in her own home, believing that children, regardless of the level of their disabilities, could learn and achieve personal growth in an environment tailored to their needs. In January 1918, Helena Devereux used $94 of saved and borrowed funds to rent a house in Devon, Pa. On May 1, 1918, she and her students took residence in the house that became known as "Devereux Stone." Soon after, her students numbered 12, and, in 1919, Devereux was able to purchase the rental property, as well as the neighboring estate. From that point, the school and subsequent organization saw continued growth, comprising different schools and facilities united under one name – Devereux Schools. In 1938, the Commonwealth of Pennsylvania granted Devereux a nonprofit charter, and it then started a Foundation that grew the programs beyond Devon, PA, to California in 1943. By that time, it also employed a director of Psychology and Education, Edward L. French, Ph.D., who subsequently became the director of the Devereux Foundation upon Helena Devereux's retirement in 1957. Today, Devereaux has campuses in Texas, Massachusetts, Connecticut, and Arizona, developed academic affiliations, and became established as a national organization with expertise in the care and treatment of people with ASD as well as other behavioral health needs (Devereaux Foundation, 2021).

In parallel with these developments, the care of people with ASD underwent major advances and transformations. These occurred largely within the academic sector, both in psychiatry, psychology, pedagogy/education, and disciplines such as occupational therapy and speech/language therapy. At the same time, the academic sector both grew its involvement in care provision as well as translation of early investigational findings to the fledgling clinical sector. These included the first formal diagnostic definitions for disorders that now come under ASD (autism by Dr. Leo Kenner in the 1930s to 1943, Dr. Hans Asperger in 1944), the early use of pharmacotherapy for aggression and agitation associated with autism (Dr. Lauretta Bender M.D. and others in the 1960s and 1970s with the advent of first generation antipsychotics), the first behavioral trials using aversives in the 1970s, and auditory integration training (Dr. Guy Berard in the 1970s). Research from academic centers also contributed to major shifts in the understanding of the phenomenology and mechanism of disease in autism and related disorders. Whereas psychoanalysis had influenced this understanding through some of the early theories around early childhood development, leading to such misinterpretations as the "refrigerator mothers or parents," "symbiotic psychosis," and "parentectomy" concepts, later academics such as Folstein and Rutter in 1977 conducted the first twin studies establishing the genetic heritability of autism, later replicated for many related childhood genetic disorders. The work of Kanner and Asperger was later refined and integrated into the diagnostic classifications for autism, Asperger's, and ASD in the *Diagnostic and Statistical Manual of the American Psychiatric Association* starting in 1980 as well as the development of systematic diagnostic tools such as the Autism Diagnostic Interview (ADI) and the Autism Diagnostic Observational Scale (ADOS). Ivar Lovaas PhD published his initial work on discrete trial learning and applied behavioral analysis in 1987, establishing a highly evidence-based methodology for treatment integrating behavioral psychology, occupational, and speech/language therapy which became the basis of subsequent early intervention services with young children and management of problematic behaviors for older children. Later, clinically impactful discoveries included the studies establishing the evidence of risperidone and aripiprazole in the management of aggression, irritabilities, and stereotypies in the early 2000s, the use of intensive behavioral, multisensory, and communication interventions for intervention with younger children, and the identification and treatment of comorbidities such as ADHD in children and youth with ASD, and toddler level screening and identification for ASD using evidence-based tools such as the M- CHAT (Wolf, 2004; Kanner, 1943; Asperger, 1944; Lovaas, 1987; Dawson et al., 2010; Robins et al., 2001).

Though the academic sector provided some services as part of the research and development work it engendered, the scope and level of these services were initially too limited to make a significant contribution to access to care. This was especially true given the rapid increase in identification of children, adolescent, and even adults with ASD as improved diagnostic criteria and phenomenological concepts were adopted. The broader access to services for people with ASD began through advocacy by organizations such as the Autism Society (founded in 1988), advocating for special education services, including behavioral services, to be delivered by public schools. This advocacy work led to the 1997 amendment for the inclusion of autism within the purview of the Individuals with Disabilities Act, originally passed by Congress in 1975 to ensure all children and youth ages 3–22 receive a free and appropriate public education regardless of any disability. For the first time, this allowed children with autism spectrum disorders access to the same level of education as other children.

In the 2000s, continued advocacy at the state and national level contributed to the start of insurance coverage for medical and applied behavioral analysis (ABA) services, which previously were denied by both Medicaid and private insurance. Most of these benefits were initially instituted state to state and capped separately from other medical and behavioral health services. It was not until the advent of the Affordable Care Act (ACA) and associated Mental Health Parity Federal legislation in 2010 that benefits and copays were set at equal levels as that of other medical and behavioral health conditions (Centers for Disease Control, 2021a, 2021b; U.S. Department of Health and Human Services, 2021).

The neurodiversity movement more recently has engaged people with ASD in their self-advocacy for recognition of rights, services, and supports while at the same time looking to de-pathologize ASD. They have focused on greater recognition of needs and rights of young adults with ASD, including an access of services and supports for transition age and adults. These include community and 4-year college campuses (also under IDEA and the Americans for Disabilities Act), as well as vocational rehabilitation services that provide employment preparation and support services, distinguishing them from those usually delivered for people with intellectual disabilities and including linguistic support and sensory accommodations (Hendricks & Wehman, 2009; Roux et al., 2013).

Service System Roles in the Care of People with ASD

Early Intervention Services

Subsequent to the inclusion of children with ASD in special education services, all 50 states instituted early intervention services for children suspected to be on the autism spectrum in the 0- to 3-year period. These services are perhaps some of the most valuable, as some studies have pointed to the reversal of signs and symptoms of autism in children without intellectual disabilities with early intensive intervention including ABA and occupational and speech therapy, usually over 20 hours weekly. These early intervention services are the closest to primary to secondary prevention level services available for ASD. Systematic screening by pediatricians with tools such as the M-CHAT for toddler age screening for ASD dovetails nicely to improve access to early intervention services. Education of parents is facilitating greater access to such services but often requires much support to families to persist through lengthy application processes (Robins et al., 2001; O'Malley, 2003; Reichow et al., 2018).

Educational System

Children with autism require comprehensive and intensive services, often combining special education, speech and language pathologists, occupational and physical therapy, behavioral services, and others, all to work together to plan, problem-solve, and administer a child's individualized educational program (IEP). These special education programs have been shown to greatly improve quality of life and allow children to succeed. An important aspect of this mandate was the inclusion of special education services for children ages 3 and above, even if not actively attending school, to enable early educational intervention in preparation to entry to preschool and kindergarten (Public Law 99-157; Education of the Handicapped Act, 1986). As more youth with ASD progress academically and attend college, extension of such services has been developed by colleges and universities, often including social supports and campus neurodiversity advocacy groups.

Specialty Services

Medical Specialties

The needs of children, youth, and adults with ASD are typically identified and addressed by the fields of Pediatrics, Developmental Pediatrics, Psychiatry/Child and Adolescent Psychiatry, and Neurology/Pediatric Neurology with the support of a broader array of specialists to address medical complexities. Parents often approach pediatricians with developmental concerns which may lead to referral to specialists with the expertise in clinical diagnostic evaluation and pharmacotherapy of interfering symptoms of ASD (mood, aggression, stereotypies) as well as comorbidities such as ADHD, tic disorders, mood disorders, and others. The training within each of these specialties covers the assessment and treatment of people with ASD from different perspectives, each with its own level of time and focus on people with ASD. There is no formal certification of specialization for ASD within or across these specialties, though some of these specialists may pursue either sub-subspecialty fellowship training in ASD or develop such expertise by virtue of their practice focus (Volkmar et al., 2014; Hyman et al., 2020). There is a growing recognition that the Medical Home Model of well-coordinated, patient-centered care is a good fit for the needs of children with ASD, especially those with medical complexity; however, a medical home may be less suited to coordinate mental health services (Todorow et al., 2018).

Psychological Specialties

Neuropsychology and Developmental Psychology are key in the systematic assessment of people with ASD, including establishing diagnoses and assessment of cognitive and intellectual function. Clinical psychologists may provide varying levels of diagnostic and therapeutic services including cognitive behavioral and social skills training. Behavioral psychologists specialize in behavioral intervention based on behavioral analysis and discrete trial learning, most often collaborating with masters' level and bachelor's level intervention specialists. Doctoral and masters' level Behavioral Psychologists can achieve Behavioral Analysis Certification when they meet criteria for specialization in ABA (Volkmar et al., 2014; Hyman et al., 2020).

Occupational Therapists, Speech/Language Therapists, and Physical Therapists

These specialties are essential in addressing sensory deficits, communication/language deficits, and motor deficits, respectively. They will often integrate cognitive behavioral approaches within their interventions or collaborate with behavioral psychologists and medical specialists (Volkmar et al., 2014; Hyman et al., 2020).

Private Providers

Many of the specialties identified above will practice independently or in small groups within their specialty or in multi-specialty groups. Some of these are oriented to serving children and youth with ASD or also with other developmental challenges (such as learning disabilities or even other behavioral health disorders). Private providers rarely have home- or community-based service options or case management to coordinate multi-agency services, even across other private providers, relying on families themselves in performing case management and coordination services. While care coordination through a pediatric medical home can improve outcomes and decrease parental stress, the cost of implementing a medical home can be burdensome for small and medium practices; clearly, systems at all levels have not finished the work of designing a seamless system of coordinated care for children (Simpser & Hudak, 2017).

Mental Health and Developmental Disorder/Intellectual Disability Agencies

The public sector was originally comprised of statewide agencies that provided services for mental health and developmental disorders. The original paradigm was laid out by the Community Mental Health Act of 1963, which established nonprofit and public community mental health centers in communities across the United States, with the goal of increasing access to ambulatory level services and reducing institutional care. Some states organized differently and had separate Developmental Disorder/Intellectual Disabilities agencies and as such either operate specialty centers or residential programs. Many of these agencies have been dismantled over time or integrated into broader mental health/behavioral health agencies. Additionally, community mental health centers have both become more generic (focusing more on mental health and addiction services) and also shifting from public funding and control to not for profit independent organizations. Many of these agencies specialize in case management and coordination services, which assist in the coordination of services by providers from different sectors, as well as in intensive home- and community-based services (Centers for Disease Control, 2021b).

The needs of children and youth on the spectrum who are in state custody (either in child welfare or juvenile justice custody or involvement) are primarily addressed through the respective state agencies. The prevalence of children with autism in foster care was 7.5% in 2001, increased to 10.5% in 2005, and then declined to 9.1% in 2007. When statistically controlled for children's age, race, sex, and state of residence, children with autism were 2.4 times more likely, and children with intellectual disability 1.9 times more likely, to enter foster care than typically developing children (Cidav et al., 2017). Currently, these agencies primarily provide case management services and use Medicaid or other state funding supports to arrange for services through community mental health or contracted private service providers, often segmented off from general services.

Some states have developed resource, coordination, and support programs for individuals with ASD rather than fund direct clinical services. These can often collaborate with established providers and academic centers. An example of these is the Centers for Autism and Related Disorders (CARDs) in the state of Florida. The Florida CARDs are a series of centers associated with different academic institutions, staffed by specialists in education, behavioral psychology, and case management. They provide families and individuals with ASD services such as referral support, case management, advocacy with school districts around educational services and rights, and socialization support services for youth with ASD, and adult transition services involving college campuses and vocational rehab agencies.

The adult developmental disabilities sector has traditionally served people with more severe intellectual disabilities, including many comorbid with ASD. This sector has been moving rapidly to deinstitutionalize individuals currently in state residential programs or facilities to community care largely involving small group home residences or home care, including the few youths in such programs. However, the behavioral support resources and staffing needed to successfully move such individuals to community care are very limited, placing them at risk of functioning at lower levels than their potential, which contributes to the frequent utilization of psychiatric emergency services, hospitalization, and overmedication. Following the US Supreme Court decision in *Olmstead v L.C* (1999), many states have been subject to class action lawsuits over the access and quality of care for its developmentally disabled citizens (O'Malley, 2003).

We are not only identifying a greater number of children with ASD but also witnessing greater numbers demonstrating the potential to achieve higher levels of education and independent function. This, combined with greater advocacy by persons with ASD and their families, has led to a growing interest in transition planning and services for adolescents moving into adulthood. For most young people, including those with ASD, adolescence and young adulthood are filled with new challenges, responsibilities, and opportunities. However, research suggests fewer young people with ASD have the same opportunities as their peers without ASD. These findings include high rates of unemployment or underemployment, low participation in education beyond high school, the majority continuing to live with family members or relatives, and limited opportunity for community or social activities, with nearly 40% spending little or no time with friends. In addition, individuals with ASD may experience changes in their ASD symptoms, behaviors, and co-occurring health conditions during adolescence and young adulthood. These changes can affect their ability to function and participate in the community. The Centers for Disease Control (CDC) has initiated various programs aimed at tracking adult outcomes and planning for future service needs at the state and local level CDC's most recent funding cycle for the Autism and Developmental Disabilities Monitoring (ADDM). Network includes support for five sites to follow up on 16-year-olds who had been identified with ASD by 8 years of age. It will provide valuable information on transition planning in special education services and potential service needs after high school. CDC's Study to Explore Early Development (SEED) began identifying children with ASD in the mid-2000s, and these children are now beginning the transition from adolescence to adulthood. Through SEED Teen, CDC is tracking the changes that occur during this transition period to learn about factors that may promote more successful transitions and better outcomes in young adults with ASD (Hendricks & Wehman, 2009; Roux et al., 2013; Dudley et al., 2019; Centers for Disease Control, 2021b). The healthcare transition of emerging adults is addressed in the final chapter of this volume.

Academic Sector

The academic sector has more recently grown its clinical services in response to both reductions in state funding and research support, leveraging its unique status in housing specialty and subspecialty services and training programs and combining translational/clinical research and service. These academic centers are often multidisciplinary, including many if not most of the above listed specialties, offering services ranging from diagnostic assessments to treatment services and supports. Some include both specialty inpatient services and community-based services. Programs may be located within medical schools/centers or main campus academic institutions and can range from specialty and multispecialty clinics to multidisciplinary centers. Those with larger scope with multiple levels of care include the Kennedy Krieger Institute at John Hopkins and Marcus Autism Center in Atlanta. Academic centers are currently growing in many parts of the United States providing added alternatives for evidence-based services. Such services are highly subscribed and rarely have ready access due to long wait times and insurance requirements.

The National Institute of Child Health and Human Development (NICHHD) supports an initiative to grow such academic centers, the Autism Centers of Excellence (ACE) Program. The ACE program is a trans-NIH initiative that supports large-scale multidisciplinary studies on autism spectrum disorders, focused on determining the disorders' etiologies and potential treatment interventions. The program includes ACE research *centers*, which foster collaboration between teams of specialists who share the same facility to address a particular research problem in depth, as well as ACE research *networks*, which consist of researchers at many facilities throughout the country, all of whom work together on a single research question.

The ACE program is funded various grant mechanisms out of the NIH, with support coming from NICHD's Intellectual and Developmental Disorders (IDD) Branch, the National Institute of Mental Health, the National Institute for Deafness and Other Communication Disorders, the National Institute of Neurological Disorders and Stroke, and the National Institute of Environmental Health Sciences. These institutes are also active members of the NIH Autism Coordinating Committee, which was created in 1997 in response to a request from Congress to enhance the quality, pace, and coordination of NIH autism research. These institutes are also members of the federal Interagency Autism Coordinating Committee, which includes representatives from various agencies within the US Department of Health and Human Services and other governmental agencies, including the US Department of Education (National Institute for Child Health and Human Development, 2021).

Residential Treatment Centers

Residential treatment centers serving people with ASD continue to operate across the United States. Where access formerly depended on primarily on private funding or charitable or state support, private third-party insurance and even public insurance have provided support for this sector/level of care. Typically, youth who are served in these programs have multiple problems and complex needs. Whereas some poorly run nonaccredited institutions may operate very basic near-custodial services with few specialist and evidence-based interventions, the great majority have adopted interdisciplinary specialty approaches with an intensive treatment model often based on ABA technology. Certification by The Joint Commission (TJC) or the Commission on Accreditation of Rehabilitation Facilities (CARF International) is essential and often required by states for qualification for Medicaid and private insurance funding of services.

Role of Funding in Transforming and Shaping ASD Services

As with most health and human services, technological advances in care and funding of care are the prime drivers in shaping the service system. The services provided to people with ASD in the last century and before were primarily residential and custodial and received meager funding by states or charitable organizations. Some charitable and state funding went toward some of early specialty services around the middle of the twentieth century. Access to those services were limited, and qualification was haphazard, depending on subjective criteria. Healthcare inequity was the norm as wealthy individuals could access private residential programs due to their direct payments or even their charitable donations.

Funding by school districts for special services under IDEA were the first services for ASD that were universally accessible to the overall population, racial disparities, and disparities of access resulting from regional funding disparities notwithstanding. Though these services were crucial in providing a level of support for some independent function, they were often restricted by eligibility criteria, often leaning toward less functional children with more obvious problems and needs that impacted their ability to make educational progress. Unfortunately, educational and school-based services have been curtailed more recently due to their high level of demand as there is higher identification of (and possibly higher prevalence) of ASD.

More recently, expanded insurance funding under Medicaid and under third-party insurance, both due to the ACA, have served to expand access to clinical services (ambulatory specialty, behavioral, and even residential services) and some educational support services (such as OT and speech therapy) outside of public schools. Unfortunately, there are arbitrary barriers that have been set up around access to such services. For example, though there is fairly ready access to medical specialty services, at times, the reimbursement level is low, and many medical providers (such as child and adolescent psychiatrists) will not accept direct insurance reimbursement at all, and some will not accept lower paying insurances. Insurance funding for many other services such as applied behavioral analysis and residential services require systematic psychological assessment using the ADOS or ADI, and as a result, there are long queues waiting for such assessment services. Additionally, with the defunding of special education, access to behavioral services within schools has decreased, while insurance companies do not allow for funding for ABA services to cross into or collaborate with schools. Such restrictions render many behavioral interventions ineffective since they cannot be developed and applied across all the child's functional settings (Centers for Disease Control, 2021a; U.S. Department of Health and Human Services, 2021).

The most challenging aspect of all is the multiple portals of entry and multiple types of providers and agencies that need to be coordinated to effectively address the needs of many if not most people with ASD. Such complexity, without highly coordinated care, often leaves parents bewildered, confused, and overwhelmed, even those with high levels of education and health literacy. Sometimes, those at the lowest socioeconomic levels who qualify for public case management services have better care coordination, though it also can falter at critical transitions, such as the transition to adult services. Adult services for ASD are significantly less developed and often are tied into public services for those with serious persistent mental illness (Centers for Disease Control, 2021a).

Racial/Ethnic Disparities

The challenges encountered in accessing and coordinating services for ASD are compounded by the structural racism within our provider agencies and systems, resulting in significant racial/ethnic disparities in identification, diagnosis, and service access and quality. A number of recent studies have begun to document such disparities. Mandell et al. (2009) studied 2568 children aged 8 years identified as meeting surveillance criteria for ASD through record abstraction from multiple sources. A total of 58% of children had a documented autism spectrum disorder. However, in adjusted analyses, Black (odds ratio [OR] = 0.79; 95% confidence interval [CI] = 0.64, 0.96), Hispanic (OR = 0.76; CI = 0.56, 0.99), or other race/ethnicity (OR = 0.65; CI = 0.43, 0.97) children were less likely than White children to have documented ASD. This disparity persisted for Black children, regardless of IQ, and was concentrated for children of other ethnicities when IQ lower than 70. Lim et al. (2020) reviewed eight studies and found that children of immigrants with ASD are diagnosed at a later age, those with limited English proficiency receive fewer service hours, and barriers include long wait times, language barriers, and limited health literacy. Magana et al. (2015), examining data from the 2005/2006 and 2009/2010 National Survey of Children with Special Health Care Needs, found racial/ethnic disparities in the quality of provider interactions were substantial in both 2005/2006 and 2009/2010. Black and Latino parents were significantly less likely than White parents to report that their provider spent enough time with their child and was sensitive to the family's values. Quebles et al. (2020) examined data for 2576 children with ASD 6–18 years old from the Autism Treatment Network (ATN) dataset. Multivariable logistic regression for age, gender, DSM-IV-TR ASD diagnosis (Autistic Disorder, PDD-NOS, Asperger's Disorder), and parents' education did not show any racial or ethnic differences in behavioral challenges, conduct problems, or sleep disturbances. Black children had lower odds of total problem behaviors; Asian children had lower odds of hyperactivity vs Whites. Racial and ethnic minority children had lower odds of total problem behaviors and conduct problems compared to Whites. Diverse children had lower odds of medication use across range of different problems except for sleep disturbance.

Obviously, culturally competent services that address access, cultural values/beliefs, and acceptability of services and provide modifications that address cultural differences are critical (Pumariega et al., 2013). At the same time, funding for services for underserved populations is also key. For example, LaClair and colleagues (2019) used quasi-difference-in-difference models to determine the effect of Medicaid waiver generosity on racial/ethnic disparities in ASD. Unmet needs among Black vs White children with ASD were roughly cut in half (13% decrease), with implementation of an average generosity waiver. No significant differences were seen for Hispanic ethnicity.

Framing ASD Services Within a Community-Based Systems of Care Model

Though we have made significant strides in evidence-based care for ASD, yet we lack a comprehensive system of care approach to address the needs of children/youth/families with ASD, including clinical, support, educational, and social needs. We have fragmented components of a system that are poorly knit together so that navigating them are too challenging for families, especially for those with less education, poorer economic resources, and families of minority children/youth who are now the numerical minority as of 2020.

Over the last 35 years, the community-based system of care model and principles have been developed in response to similar problems with fragmentation of care and lack of appropriate access in child mental health, particularly for children and families with multiple problems and needs. These principles are based on a flexible and individualized approach to service delivery for the child and family within the home and community as an alternative to treatment in out-of-home settings while attending to family and systems issues that impact such care. The key principles include access to a comprehensive array of services, treatment individualized to the child's needs, treatment in the least restrictive environment possible, full utilization of family and community resources, full participation of families and youth as partners in service planning and delivery, interagency coordination, the use of case management for service coordination, no ejection or rejection from services due to lack of "treatability" or "cooperation" with interventions, early identification and intervention, smooth transition of youth into the adult service system, effective advocacy efforts, and non-discriminating, culturally sensitive services (Winters et al., 2007) (see Table 4.1).

Table 4.1 The Community-based Systems of Care Model shares key principles with the Pediatric Medical Home Model

The Community-Based Systems of Care Model	The Pediatric Medical Home Model
1. Full participation of families and youth as partners in services planning and delivery of culturally sensitive, non-discriminating services	1. Developmentally appropriate and culturally competent family-centered care with shared decision-making guiding care
2. Provision of a comprehensive array of services	2. Provision of comprehensive primary care
3. Treatment guided by an individualized treatment plan developed collaboratively with the family	3. Care guided by a shared plan of care developed in collaboration with the family
4. Early identification and intervention	4. Coordination with early intervention programs
5. The use of case management for individualized service coordination	5. Care coordination with pediatric medical subspecialists and surgical specialists
6. Full utilization of family and community resources	6. Continuity of care between ambulatory and inpatient settings
7. Smooth transition of youth into the adult service system, effective advocacy efforts	7. Organized, well-planned transitions, including transition to adult-oriented health care, work, and independence
8. Interagency coordination at a systems level	8. Providing clear and unbiased information
9. Treatment in the least restrictive environment possible	9. Providing family access to a comprehensive, central record
10. No ejection or rejection from services due to lack of "treatability" or "cooperation" with interventions	10. All insurance accepted, with changes accommodated

Adapted from Winters et al. (2007); Medical Home Initiatives for Children With Special Needs Project Advisory Committee (2002)

Family-driven care is a cornerstone of the system-of-care model and has had a significant influence on national policy for both child and adult mental health (33–35). The child and family drive the clinical planning process through determining the goals and desired outcomes of services, selecting the composition of the interagency service planning team, evaluating the effectiveness of services, and having a meaningful role in all decisions, including those that impact funding of services. The interagency planning team typically has representatives from all the agencies and sectors involved with the child, and the team process facilitates interagency and interdisciplinary collaboration. The complementary contributions of various team members function synergistically in identifying system and community resources to promote better outcomes (Winters et al., 2007).

For children with complex problems involved in multiple child-serving agencies, assessment and treatment planning are primarily accomplished through interdisciplinary clinical teams. These teams bring together different clinical and support resources to address the child's needs to supporting him/her and their family in their community environment. Teams use the wraparound process, a specific model of a child- and family-driven team planning process that has been empirically tested within systems of care. Wraparound is a definable, integrated planning process that results in a unique set of community services and natural supports that are individualized for a child and family to achieve a set of positive outcomes. The wraparound process builds on the strengths of the child and family, is community-based (using a balance of formal and informal supports), is outcome-driven, and provides unconditional care. The use of a strength-based orientation and discussion of needs rather than problems promote more active engagement by families in service planning activities. Interventions designed to reinforce strengths of the child and family may include nontraditional therapies such as specific skills training or mentored work experiences that remediate or offset deficits. These interventions generally are not included in traditional categorical funding and may require flexible funds that are not assigned to specific service types. Care management is key for the wraparound process so that different services and different interventions can be well-coordinated and integrated for greatest effectiveness, and not duplicated (Winters et al., 2007).

Family participation is also facilitated through the parallel development of child and family teams (CFTs). CFTs are composed primarily of nonprofessional members led by the consumer family, usually a parent. In cases of older youth as consumers, the youth may serve as team leader. Empowering youth and families to assume a central role in outlining treatment goals and planning requires the involvement of specially trained individuals who can guide families to develop such goals. CFTs collaborate with interdisciplinary teams and professionals in agencies providing services. The CFT creates an overall care plan, including a crisis plan. The clinical team then negotiates their role in the crisis and care plans. This negotiation further educates families about how their child's needs could be addressed through treatment and enables professionals to learn about the realities faced by the family (Winters et al., 2007).

More recently, service quality, cost-effectiveness, and outcomes and integration of evidence-based practices have received greater emphasis within community-based systems of care programs. An example of such emphasis has been the multisite national evaluation of the Comprehensive Mental Health Services Program for Children and Their Families. This program, which has funded over 100 local and regional systems of care programs, has evaluations both over baseline ratings at the start of the programs and matched control evaluations. These have demonstrated significant improvement in child and family function using objective measures, reduced suicidality, reduced racial/ethnic disparities, increased stability of living situation, reduced hospitalizations, and reduced cost of care in other service sectors such as education, juvenile justice, child welfare, and general health, with correlations of outcomes to fidelity to system of care principles (U.S. Department of Health and Human Services, 2015).

To date, there has been limited application of the community-based system of care principles and model in the realm of services for people with ASD. However, the parallels between the challenges in caring for children with serious emotional disturbances and people on the autism spectrum are significant, and these populations often overlap. The ideal application of the system of care model for people with ASD would have basic medical, developmental, and behavioral health services coordinated through the Pediatric Medical Home, which is increasingly recognized at the "hub" for ASD services and supports. The Pediatric Medical Home shares many principles and elements with the community-based mental health systems model (Asarnow et al., 2017) (see Table 4.1). An adjunctive entity that has recently surfaced nationally and is closely tied to pediatric medical homes is Pediatric Behavioral Health Collaborative Programs. These provide the supports that are often necessary for pediatric primary care providers to access entry level behavioral health (and often developmental) services, including consultation (telephonic or televideo) with child and adolescent psychiatrists, psychologists, and licensed social workers, assistance with care coordination services to assist families in accessing community resources, ongoing training and skill building support, and technical assistance for practices to integrate behavioral health services within the practice's care processes. This model has been effective in facilitating primary management of entry level to moderate behavioral health needs in primary care. This collaboration can also identify children and youth with ASD with complex needs who require a more interdisciplinary coordinated care approach (Asarnow et al., 2015; Pumariega et al., 2016).

For children, youth, and adults with ASD who have such complex needs, more intensive care could be coordinated at the local level using interdisciplinary teams and child and family teams. These teams could pursue comprehensive assessment and treatment planning, bring in the necessary medical and behavioral specialists/disciplines from their respective sectors (private, public, academic, nonprofit, etc.) to negotiate service/treatment plans with families and affected persons, implement such plans, address arbitrary barriers to access to care and care coordination (e.g., between private/academic and public providers, across schools and applied behavioral analysis providers), and blend funding sources for different types and levels of services. Such interdisciplinary teams would be significantly more clinically effective and cost-effective. State entities that currently provide limited support and referral services could provide the oversight, structure, and case management support and serve a convening function for such teams, with incentives from enhanced funding for team participation (as opposed to solo treatment in silos) and empower such teams by streamlining eligibility and access procedures. More uniform standards around the qualifications of service providers and application of evidence-based interventions to fidelity by such care coordinating entities could also greatly enhance such approaches. The primary care provider within the Pediatric Medical Home and the pediatric behavioral health collaborative program would continue to be central and engaged within these teams.

A core technology for the operation of such teams would need to be behavioral analysis and discrete trial learning with multiple baseline designs, with all interventions the youth or adult receive being coordinated and measured in terms of reduction of agreed-upon target behavioral outcomes. Multiple baseline designs lend themselves nicely to objective measurement of outcomes for individual sand could be used in the aggregate to learn more about treatment and service effectiveness.

The orientation to least restrictive environment of care for system of care programs could bring greater emphasis on home-, school-, and community-based services for people with ASD, leaving residential services for highly unmanageable youth and adults. Objective level of care tools based on systems of care principles could be used to determine level of care intensity need. One such tool, the CALOCUS/CASII (Fallon et al., 2006) is not only directly applicable to this goal but is designed to be used within developmental disorders settings. There are positive outcomes that could result from this greater emphasis, with identification of key services. For example, Mandell et al. (2012) examined the use of respite care and therapeutic services, based on procedure codes, versus hospitalizations associated with a diagnosis of ASD. They found that each $1000 increase in spending on respite care during the preceding 60 days resulted in an 8% decrease in the odds of hospitalization in adjusted analysis. The use of therapeutic services was not associated with reduced risk of hospitalization.

A system of case model with a public health orientation would also enhance data collection to assist in advocacy for improved service funding. We continue to find inadequate funding, especially from the private insurance sector, for community-based services that often result in higher institutionalization and lower community functionality for people with ASD. For example, Wang et al. (2013) compared healthcare costs and service use for autism spectrum disorder (ASD) between Medicaid and private insurance, using 2003 insurance claims data in 24 states. In terms of costs and service use per child with ASD, Medicaid had higher total healthcare costs ($22,653 vs. $5254), higher ASD-specific costs ($7438 vs. $928), higher psychotropic medication costs ($1468 vs. $875), more speech therapy visits (13.0 vs. 3.6 visits), more occupational/physical therapy visits (6.4 vs. 0.9 visits), and more behavior modification/social skills visits (3.8 vs. 1.1 visits) than private insurance (all $p < 0.0001$). In multivariate analysis, being enrolled in Medicaid had the largest effect on costs, after controlling for other variables. These findings emphasize the need for continued efforts to improve private insurance coverage of autism. More recently, Liu et al. (2021) used 2008–2013 Medicaid data to conduct a retrospective cohort study to evaluate the effect of Medicaid home- and community-based services (HCBS) waiver programs on emergency department (ED) utilizations among youth with autism spectrum disorder (ASD). They showed that annual ED utilization rates were 13.5% and 18.8% for individuals on autism-specific and intellectual and developmental disabilities (IDD) waivers, respectively, vs. 28.5% for those without a waiver. Compared to no waivers, autism-specific waivers (adjusted odds ratio, 0.62; 95% confidence interval, [0.58–0.66]) and IDD waivers (0.65; [0.64–0.66]) were strongly associated with reduced ED utilization. These findings suggest that HCBS waivers are effective in reducing the incidence of ED visits among youth with ASD.

Conclusion

It is clear that services for people with ASD will continue to grow in scope and demand over the coming decades as we better identify and diagnose affected individuals. Scientific advances, particularly in prevention science and neurobiology, might mitigate the societal and family costs and burdens that are associated with this growth. However, equal savings and increase in effectiveness can result from service system reform that can right-size services (enhance community-based and reduce higher cost hospital and residential) and enhance service coordination/integration and family and youth engagement.

References

Asarnow, J. R., Rozenman, M., Wiblin, J., & Zeltzer, L. (2015). Integrated medical-behavioral care compared with usual primary care for child and adolescent behavioral health: A meta-analysis. *JAMA Pediatrics, 169*(10), 929–937.

Asarnow, J. R., Kolko, D. J., Miranda, J., & Kazak, A. E. (2017). The pediatric patient-centered medical home: Innovative models for improving behavioral health. *American Psychologist, 72*(1), 13.

Asperger, H. (1944). Die “autistichen Psychopathen” im Kindersalter. Archive fur psychiatrie und Nervenkrankheiten. (U. Frith, Trans.) (Ed.) (1991). In *Autism and Asperger's syndrome* (Vol. 117, pp. 76–136). Cambridge University Press.

Blaxill, M., Rogers, T., & Nevison, C. (2021). Autism Tsunami: The impact of rising prevalence on the societal cost of autism in the United States. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-021-05120. Accessed on August 1, 2021.

Centers for Disease Control. (2021a). *Accessing services for autism spectrum disorder*. https://www.cdc.gov/ncbddd/autism/accessing-services-for-autism-spectrum-disorder.html. Last accessed on August 2, 2021.

Centers for Disease Control. (2021b). *Treatment and intervention services for autism spectrum disorder*. https://www.cdc.gov/ncbddd/autism/treatment.html. Last accessed on August 1, 2021.

Cidav, Z., Munson, J., Estes, A., Dawson, G., Rogers, S., & Mandell, D. (2017). Cost offset associated with early start Denver model for children with autism. *Journal of the American Academy of Child and Adolescent Psychiatry, 9*, 777–783. https://doi.org/10.1016/j.jaac.2017.06.007. PMID: 28838582.

Dawson, G., Rogers, S., Munson, J., Smith, M., Winter, J., Greenson, J., Donaldson, A., & Varley, J. (2010). Randomized, controlled trial of an intervention for toddlers with autism: The early start Denver model. *Pediatrics, 125*(1), e17–e23.

Devereaux Foundation. (2021). *The history of Devereaux advanced behavioral health*. https://www.devereux.org/site/SPageServer/?pagename=history. Last accessed on August 2, 2021.

Donvan, J., & Zucker, C. (2016, January/February). The early history of autism in America. *Smithsonian Magazine*. https://www.smithsonianmag.com/science-nature/early-history-autism-america-180957684/. Last accessed on August 2, 2021.

Dudley, K. M., Klinger, M., Meyer, A., Powell, P., & Klinger, L. (2019). Understanding service usage and needs for adults with ASD: The importance of living situation. *Journal of Autism and Developmental Disorders, 49*(2), 556–568.

Education of the Handicapped Act Amendments of 1986, 20 U.S.C. §140 et seq. (1986). https://www.govinfo.gov/content/pkg/STATUTE-100/pdf/STATUTE-100-Pg1145.pdf. Last accessed on August 14, 2021.

Fallon, T., Pumariega, A. J., Sowers, W., Klaehn, R., Huffine, C., Vaughan, T., Winters, N., Chenven, M., Marx, L., Zachik, A., Heffron, W., & Grimes, K. (2006). A level of care instrument for children's systems of care: Construction, reliability, and validity. *Journal of Child and Family Studies, 15*, 140–152.

Hendricks, D. R., & Wehman, P. (2009). Transition from school to adulthood for youth with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities, 24*(2), 77–88.

Hyman, S. L., Levey, S. E., & Myers, S. M. (2020). Council on Children with Disabilities, Section on Developmental and Behavioral Pediatrics. Identification, evaluation, and management of children with autism spectrum disorder. *Pediatrics, 145*(1), e20193447.

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child, 2*, 217–250.

LaClair, M., Mandell, D., Dick, A., Iskandarani, K., Stein, B., & Leslie, D. (2019). The effect of Medicaid waivers on ameliorating racial/ethnic disparities among children with autism. *Health Services Research, 54*, 912–919.

Lim, N., O'Reilly, M., Sigafoos, J., Lancioni, G., & Sanchez, N. (2020). A review of barriers experienced by immigrant parents of children with autism when accessing service. *Review Journal of Autism and Developmental Disorders, 8*, 366–372. Published online. https://doi.org/10.1007/s40489-020-00216-9. Accessed on August 1, 2021.

Liu, G., Velott, D., Kong, L., Dick, A., Mandell, D., Stein, B., Murray, M., Ba, D., Cidav, Z., & Leslie, D. (2021). The association of the Medicaid 1915(c) home and community-based services waivers with emergency department utilization among youth with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 52*(4), 1587–1597. https://doi.org/10.1007/s10803-021-05060-2. Last accessed on August 1, 2021.

Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology, 55*(1), 3–9. https://doi.org/10.1037/0022-006x.55.1.3. ISSN 1939-117. PMID 3571656.

Magana, S., Parish, S., & Son, E. (2015). Have racial and ethnic disparities in the quality of health care relationships changed for children with developmental disabilities and ASD? *American Journal on Intellectual and Developmental Disabilities, 120*(6), 504–513.

Mandell, D., Wiggins, L., Carpenter, L., Daniels, J., DiGuiseppi, C., Durkin, M., Giarelli, E., Morrier, M., Nicholas, J., Pinto-Martin, J., Shattuck, P., Thomas, K., Yeargin-Allsop, M., & Kirby, R. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health, 99*, 493–498.

Mandell, D., Xie, M., Morales, K., Lawer, L., McCarthy, M., & Marcus, S. (2012). The interplay of outpatient services and psychiatric hospitalization among Medicaid-enrolled children with autism spectrum disorders. *Archives of Pediatrics and Adolescent Medicine, 166*(1), 68–73. https://doi.org/10.1001/archpediatrics.2011.714

Medical Home Initiatives for Children With Special Needs Project Advisory Committee. (2002). Reaffirmed 2008. The medical home. *Pediatrics, 110*(1), 184–186.

National Institute for Child Health and Human Development, National Institutes of Health, U.S. Department of Health and Human Services. (2021). *Autism Centers of Excellence (ACE) Program*. https://www.nichd.nih.gov/research/supported/ace. Last accessed on August 1, 2021.

O'Malley, K. (2003). Youth with comorbid disorders. In A. J. Pumariega & N. C. Winters (Eds.), *Handbook of community systems of care; the new child & adolescent community psychiatry* (pp. 276–315). Jossey Bass Publishers.

Olmstead v L.C 527 U.S. 581 (1999).

Pumariega, A. J., Rothe, E., Mian, A., Carlisle, L., Toppelberg, C., Harris, T., Gogineni, R., Webb, S., Smith, J., & American Academy of Child and Adolescent Psychiatry (AACAP) Committee on Quality Issues (CQI). (2013). Practice parameter for cultural competence in child and adolescent psychiatric practice. *Journal of the American Academy of Child and Adolescent Psychiatry, 52*(10), 1101–1115.

Pumariega, A. J., Roberts, M., Naydock, G., Solkhah, R., Hanbury, R., Kairys, S., & Kelley, P. (2016). Pediatric Psychiatry Collaborative: New Jersey model program and cases. *New Jersey Pediatrics, Fall 2016*, 6–11. ISSN 2375-477X

Quebles, I., Solomon, O., Smith, K., Rao, S., Lu, F., Azen, C., Anaya, G., & Yin, L. (2020). Racial and ethnic differences in behavioral problems and medication use among children with autism spectrum disorders. *American Journal on Intellectual and Developmental Disabilities, 125*(5), 369–388. https://doi.org/10.1352/1944-7558-125.5.369

Reichow, B., et al. (2018). Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews, 5*, CD009260.

Robins, D., Fein, D., Barton, M., & Green, J. (2001). The modified checklist for autism in toddlers: An initial study investigating the early detection of autism and pervasive developmental disorders. *Journal of Autism and Developmental Disorders, 31*(2), 131–144.

Roux, A. M., et al. (2013). Postsecondary employment experiences among young adults with an autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry, 52*(9), 931–939.

Simpser, E., & Hudak, M. L. (2017). Financing of pediatric home health care. *Pediatrics, 139*(3), e20164202.

Todorow, C., Connell, J., & Turchi, R. M. (2018). The medical home for children with autism spectrum disorder: An essential element whose time has come. *Current Opinion in Pediatrics, 30*(2), 311–317.

U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration Center for Mental Health Services, Child, Adolescent and Family Branch. (2015). *The comprehensive community mental health services for children with serious emotional disturbances program, report to Congress, 2015.* Publication No. PEP16-CMHI2015.

U.S. Department of Health and Human Services. (2021). *The affordable care act and autism and related conditions.* https://www.hhs.gov/programs/topic-sites/autism/aca-and-autism/index.html. Last accessed on July 31, 2021.

Volkmar, F., Siegel, M., Woodbury-Smith, M., King, B., McCracken, J., State, M., & American Academy of Child and Adolescent Psychiatry (AACAP) Committee on Quality Issues (CQI). (2014). Practice parameter for the assessment and treatment of children and adolescents with autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry, 53*(2), 237–257.

Wang, L., Mandell, D., Lawer, L., Cidav, Z., & Leslie, D. (2013). Healthcare service use and costs for autism spectrum disorder: A comparison between Medicaid and private insurance. *Journal of Autism and Developmental Disorders, 43*, 1057–1064.

Winters, N. C., Pumariega, A. J., & Work Group on Community-Based Systems of Care, Committee on Community Psychiatry, & Work Group on Quality Issues Practice Parameters for Child Mental Health in Systems of Care. (2007). Practice parameter on child and adolescent mental health care in community systems of care. *Journal of the American Academy of Child and Adolescent Psychiatry, 46*(2), 284–299.

Wolf, S. (2004). The history of autism. *European Child and Adolescent Psychiatry, 13*, 201–208. https://doi.org/10.1007/s00787-004-0363-5