



# Optimizing Care for Autistic Patients in Health Care Settings: A Scoping Review and Call to Action

Holly K. Harris, MD; Laura Weissman, MD; Eron Y. Friedlaender, MD, MPH; Ann M. Neumeyer, MD; Alexander J. Friedman, MPH; Sarah J. Spence, MD, PhD; Chloe Rotman, MLIS; Shari Krauss, MA, MPH; Sarabeth Broder-Fingert, MD, MPH; Carol Weitzman, MD

From the Department of Pediatrics (HK Harris), Baylor College of Medicine and Meyer Center for Developmental Pediatrics, Texas Children's Hospital, Houston, Tex; Division of Developmental Medicine (L Weissman and C Weitzman), Boston Children's Hospital and Harvard Medical School, Boston, Mass; Department of Pediatrics (EY Friedlaender), Perelman School of Medicine, University of Pennsylvania, Philadelphia, Pa; Lurie Center for Autism (AM Neumeyer), Massachusetts General Hospital and Harvard Medical School, Boston, Mass; Division of Developmental and Behavioral Pediatrics (AJ Friedman and S Krauss), Boston Medical Center, Boston, Mass; Division of Neurology (SJ Spence), Boston Children's Hospital and Harvard Medical School, Boston, Mass; Medical Library (C Rotman), Boston Children's Hospital, Boston, Mass; Department of Pediatrics (S Broder-Fingert), UMASS Chan Medical School, Worcester, Mass  
Address correspondence to Holly K. Harris, MD, Division of Developmental Pediatrics, Meyer Center for Developmental Pediatrics and Autism, 8080 North Stadium Drive, Houston, Tex 77054 (e-mail: [holly.harris@bcm.edu](mailto:holly.harris@bcm.edu)).

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## ABSTRACT

**OBJECTIVE:** We conducted a scoping review of interventions designed to improve the health care experiences of autistic individuals and assessed the methodology and outcomes used to evaluate them.

**METHODS:** Literature from January 2005 to October 2020 was searched using PubMed, Excerpta Medica dataBASE (EMBASE), Cumulated Index to Nursing and Allied Health Literature (CINAHL), PsycINFO as well as hand searching. Studies included described an intervention for autistic individuals in inpatient or outpatient settings and evaluated the intervention using standardized methodology. Results were exported to Covidence software. Ten reviewers completed abstract screening, full text review, and then systematic data extraction of the remaining articles. Two reviewers evaluated each article at each stage, with a third reviewer arbitrating differences.

**RESULTS:** A total of 38 studies, including three randomized controlled trials (RCTs) were included. Twenty-six (68%) took

place in dental, psychiatric, or procedural settings. Interventions primarily focused on visit preparation and comprehensive care plans or pathways (N = 29, 76%). The most frequent outcome was procedural compliance (N = 15), followed by intervention acceptability (N = 7) and parent satisfaction (N = 6). Two studies involved autistic individuals and caregivers in study design, and no studies assessed racial/ethnic diversity on intervention impact.

**CONCLUSIONS:** Well-designed evaluations of interventions to support autistic individuals in pediatric health care settings are limited. There is a need to conduct large multi-site intervention implementation studies.

**KEYWORDS:** autism; health equity; inpatient care; outpatient care

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### What this Scoping Review Adds

- Identifies studies that assess interventions aimed to improve the health care experiences of autistic individuals.
- Identifies studies with a clear methodology and quantifiable outcomes.
- Includes all inpatient and outpatient pediatric health care settings.

### How to Use this Scoping Review

- Advocate for more rigorous intervention implementation research endeavors.
- Recognize the need to adapt health care settings for autistic individuals.
- Identify ways to improve the health care experiences of autistic individuals in one's own setting.

## BACKGROUND

Autism Spectrum Disorder (ASD) currently affects one in 36 children.<sup>1</sup> Approximately 70% of autistic individuals have co-occurring health conditions that include neurological, gastrointestinal, respiratory and psychiatric issues<sup>2–5</sup> resulting in increased health care utilization across inpatient, outpatient, psychiatric and emergency department settings.<sup>4,6,7</sup> Further, rates of hospitalization for autistic children have risen more than for typical peers and exceed rates for children with other neurodevelopmental disorders including intellectual disability, Down syndrome and cerebral palsy.<sup>8,9</sup> Increased admission for autistic patients has largely been explained by the high rates of comorbid mental and behavioral health challenges in this population coupled with scarce outpatient resource availability. Length of stay in all settings for autistic children is significantly longer when compared with typical peers, possibly due to a high number of co-occurring conditions or difficulty in delivering care.<sup>8</sup>

Given the higher rates of co-occurring conditions and health care utilization, combined with care disparities, unmet health care needs, and marginalization within medical settings, it follows that there is overall higher morbidity and mortality for autistic individuals.<sup>10,11</sup> Autistic individuals have been shown to exhibit decreased access to quality health care and even greater health inequities when compared to patients with other developmental-behavioral conditions or special health care needs.<sup>7,12–14</sup> This has been presumed a consequence of the challenges that medical environments present such as sensory triggers like loud noises, bright lights and aversive touch; frequent and unpredictable change to routine with variable wait times and unexpected tests and treatments; communication challenges; and a high level of uncomfortable social demands and anxiety with frequently changing staff. These difficulties can lead to challenging behaviors that may result in incomplete procedures, restraint, higher rates of missed appointments and forgone care. In fact, in September 2023, the National Institute on Minority Health and Health Disparities (NIMHD) formally designated individuals with disabilities, including autism, as a population experiencing health care disparities for National Institutes of Health (NIH) research.<sup>15</sup>

There has been a growing interest across a range of health care settings in improving access to quality care by reducing these barriers. Many interventions have focused on broadening caregiver training,<sup>16–19</sup> providing more visit preparation and support,<sup>20,21</sup> and modifying environmental demands,<sup>22–26</sup> along with system changes that depend on the strength of multidisciplinary collaborative teams.<sup>27</sup> However, the evaluation of most interventions is limited. Two recent reviews, one scoping review and one systematic review, examining interventions to reduce barriers to health care access for autistic individuals identified a limited number of studies (N = 23 and 31 respectively).<sup>6,10</sup> Many of the studies included in these reviews lacked quantifiable outcomes or specific details regarding a given intervention's delivery or efficacy, or lacked empirical data.<sup>6,10</sup> Neither review included a substantial number of essential health care and

mental health settings frequented by autistic patients, either excluding dental, perioperative and/or mental health settings and thus potentially missing important data from these areas. Including mental and behavioral health care settings is particularly important and timely given rising suicide rates among US adolescents including those with autism. In addition, limited space in inpatient and outpatient mental health treatment programs means autistic youth are frequently cared for in emergency rooms or other acute or inpatient environments that are often unprepared to meet their needs but remain the safety net for families, making barriers to care in these settings especially important to understand and address.<sup>28,29</sup>

Therefore, the present study undertook a scoping review of the literature on interventions designed to improve the health care experiences for autistic individuals to 1) determine the extent of available research 2) assess which medical settings are represented in the literature, 3) identify the methodologies used and 4) assess the adequacy of the current literature to summarize the state of the art in this area, as well as identify any existing gaps. Given that the evidence regarding interventions to improve health care of autistic individuals is broad and ill-defined, this team determined that a scoping review was most appropriate to address our aims. Scoping reviews support a defined investigative process in which the body of literature on a given topic is still emerging and without a specific question typically necessary to conduct a systematic review.<sup>30</sup> Our work was driven by the following question: Are there studies that have utilized sound research methodology and measurable outcomes in order to evaluate the effectiveness of interventions to promote optimization of health care experiences of autistic children and/or adults? Unlike prior reviews, we included all potential health care settings (dental, psychiatric, perioperative, procedural, emergency departments, inpatient and outpatient settings) to ensure we captured the complete landscape of interventions across all health care settings. This review is critical to assess the current evidence supporting practice for facilitating and bettering care for autistic individuals so that gaps can be clearly elucidated and a sound research agenda may be developed to inform operationalization of findings.

## METHODS

### STUDY DESIGN

This scoping review was developed in accordance with the methodology and guidance developed by the Joanna Briggs Institute<sup>31</sup> and followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist to report the study rationale, methodology, results, and discussion.<sup>32</sup>

### SEARCH STRATEGY AND INFORMATION SOURCES

Literature from January 2005 to August 2023 was reviewed via a search conducted by a medical librarian, using PubMed, EMBASE, CINAHL, and PsycINFO. Hand searching was also utilized to capture new, relevant

publications. The medical librarian and authors identified keywords that included but were not limited to “barrier\*,” “strategies,” “checklist\*,” “tool kit,” “quality improvement,” “time to care,” “care quality,” and “readmission.” Search strategies for all databases are available in the [Appendix](#). January 2005 was used as a cut-off date for results to ensure the papers identified were reasonably current. The searches were limited to English-language articles. Results were deduplicated in EndNote, then exported to Covidence review software for screening by the team. In order to identify any additional relevant studies that may have been omitted from our electronic search, the reference list of the two most recent published reviews,<sup>6,10</sup> including articles that were included in their final results, were hand searched to determine if they were suitable for inclusion.

### INCLUSION AND EXCLUSION CRITERIA

Studies were considered for inclusion if they described a specific intervention designed to improve the health care experience for an autistic child or adult and included an evaluation of the intervention where data were collected, and results were reported. Interventions could target a number of different parties including autistic children or adults, parents and caregivers, staff, and providers but also system change. Interventions needed to occur within health care and/or mental health settings so any intervention occurring in educational settings was excluded. We only included manuscripts that were published in a peer-reviewed journal and were written in English. Studies that simply described a problem or interventions without any assessment using standard, accepted research methodologies were excluded. Case reports, dissertations and theses, and studies of treatments for ASD and co-occurring conditions associated with ASD were excluded as well as interventions designed to improve screening and diagnosis and provider knowledge of ASD.

### SELECTION OF SOURCES OF EVIDENCE

Ten reviewers completed the data extraction beginning at the level of title and abstract screening, progressing to full text review, followed by data extraction. Two members of the research team (LW and CCW) a priori developed a data abstraction tool that included the following variables that were extracted from articles that were included: author, title, year of publication, country, study design, type of intervention, setting, participants, number and age range of participants, primary outcome, and whether there was a positive or negative effect. Secondary outcomes and relevant data (participants involved and effect of the secondary outcome) were also abstracted if present. The study design variable was defined a priori and the extraction was mapped to the potential choices (i.e. RCT, descriptive study, survey research, etc). Once extraction had occurred, the type of intervention and primary outcome variables were then grouped into categories that were defined based on the common results that had arisen within these categories. All papers at each stage of the process were reviewed by two members of the team. Any disagreements in

ratings by the pair underwent assessment by a third reviewer. The team met regularly to resolve any variance between reviewers, and the team coded numerous publications together to ensure consistency in the application of inclusion and exclusion criteria amongst reviewers. Inclusion criteria and the data abstraction form were adjusted in an iterative process to ensure the final studies included in the review represented a comprehensive overview of the existing literature that focused on intervention studies, included an evaluation using standard accepted research methodology and reflected the intended population, concept and context of the study.

## RESULTS

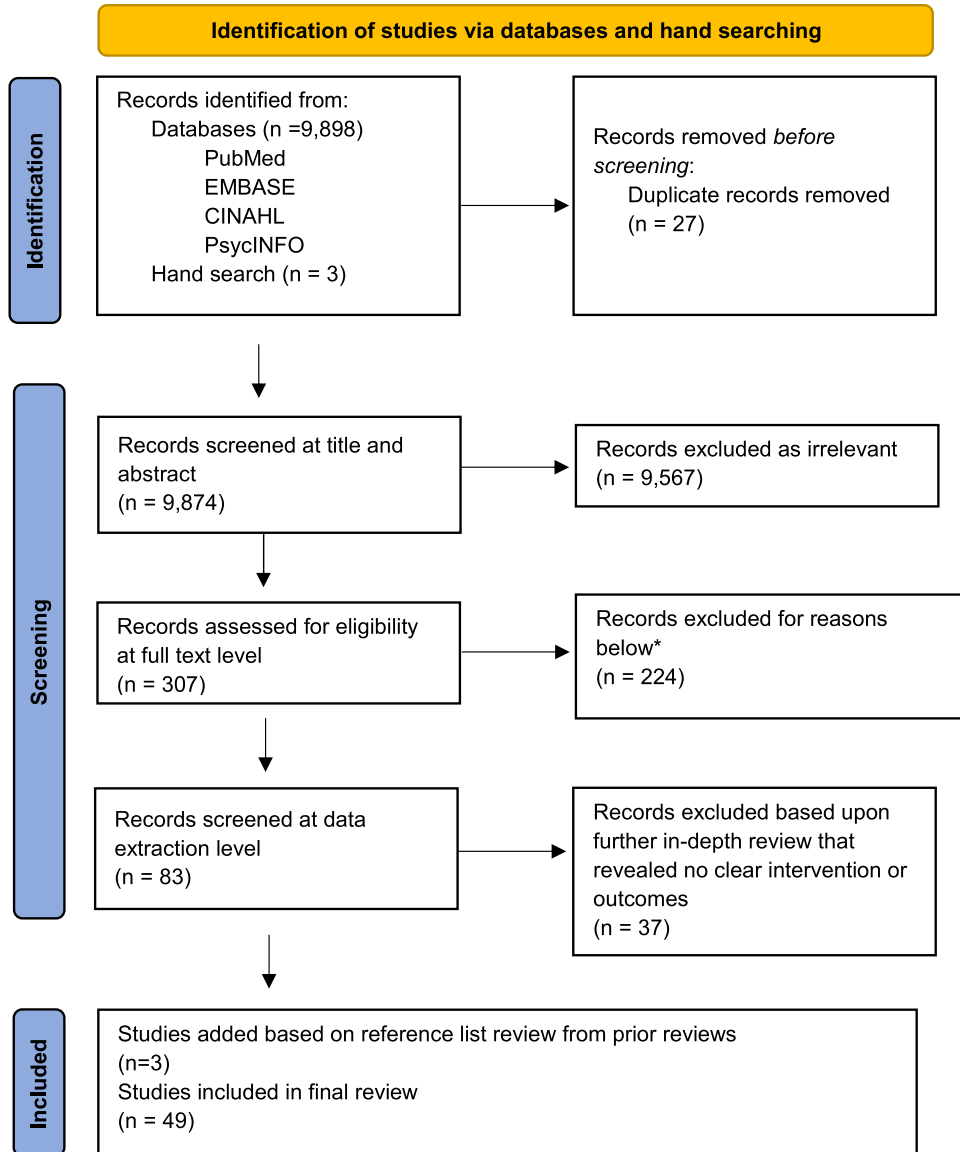
[Figure](#) is a PRISMA flow diagram that outlines study selection. Of the initial 9898 results, 307 met criteria for full text review. Of those, 83 were included for data extraction. Thirty-seven of these papers did not meet inclusion criteria. An additional three papers were added after a review of the publications included in prior reviews on this topic<sup>6,10</sup> resulting in a total of 49 papers evaluated for the final analysis (included references in this scoping review are indicated by an asterisk in our reference list; [Table 1](#)).<sup>18–21,25,33–76</sup>

### SETTING

Of the 49 papers included, the majority (N = 34, 69.4%) were completed in the United States with the remaining research primarily coming from Canada and the UK ([Table 2](#)). Outpatient dental settings were the most common site where studies were conducted (N = 17, 34.7%) followed by inpatient procedural settings, such as the operating room, (N = 11, 22.4%) followed by inpatient psychiatric settings (N = 6, 12.2%). Eighteen (36.7%) were completed in inpatient pediatric settings (including pediatric emergency department and procedural/surgical settings) and 31 (63.3%) in outpatient or pediatric specialty settings.

### TYPE OF INTERVENTIONS

Half of the interventions targeted visit preparation and support in advance of or during an encounter (N = 26, 53.0%). Interventions of this nature used a range of accommodations to support autistic individuals cope more effectively with health care encounters and medical procedures. These interventions typically involved: 1) desensitization programs that occurred in advance of a procedure or visit and allowed for practice of procedures, familiarity with materials, and graduated exposure, 2) use of social stories and visual schedules during the encounter, 3) picture exchange systems and other communication devices during the encounter, 4) behavioral techniques such as reinforcement schedules and establishing a hierarchy of tasks either before or during the encounter, 5) psychoeducation about procedures and visits before the encounter, 6) media interventions such as the use of an iPad and texting to reduce wait time, and 7)



**Figure.** Modified PRISMA flow diagram for scoping review. \*Reasons for exclusion at full text level: No clear outcome,  $n = 85$ ; No full text available,  $n = 40$ ; No clear study design,  $n = 38$ ; Review article only,  $n = 16$ ; No clear intervention,  $n = 12$ ; Wrong patient population,  $n = 9$ ; Wrong setting,  $n = 3$ ; Letters to the Editor,  $n = 2$ ; Consensus paper,  $n = 1$ ; Dissertation,  $n = 1$ ; Duplicate,  $n = 1$ . PRISMA indicates preferred reporting items for systematic reviews and meta-analyses.

sensory regulation tools and distraction materials for use during an encounter.

The next most common type of intervention was the development of a comprehensive care plan or clinical pathway ( $N = 12$ , 24.5%). Comprehensive care pathways were primarily used in surgical and psychiatric settings and involved a systems approach, involving the coordination of care amongst many disciplines including child life, nursing, and medical professionals. Care pathways often involved pre-visit planning, team discussion, environmental and scheduling modifications such as adjusting the time of day for procedures or hospital arrival time and accommodative interventions to help the child cope with the procedure, visit or hospitalization more effectively. One study evaluated hospital wide interventions that involved multiple departments and professionals across the health care system, such as having specialized

coordinators, online nursing training across patient care units or utilization of individualized care plans across the health care system.

The third most common intervention was staff education and training ( $N = 8$ , 16.3%) on characteristics and specific challenges for autistic individuals in health care settings, the use of toolkits specifically designed for autistic patients, development of care plans, and/or managing complex behaviors. Most staff educational programs were didactic in nature, some were conducted online while others were instructor led. Educational interventions varied in intensity, with two studies providing between nine and 18 hours of material, versus others that were limited to 15 minutes to 1 hour (range: 15 minutes to 18 hours of training).

Three studies ( $N = 3$ , 6.1%) incorporated systems changes and all three evaluated tailored inpatient units for

Table 1. Studies Included in Scoping Review

Author (Date)	Title	Setting	Participants (N)	Study Design	Intervention Type	Outcome	Outcome Effect
AlHurmaid (2016)	Effectiveness of the D-TERMINED Program of Repetitive Tasking for Children with Autism Spectrum Disorder	Dental	Autistic children (44)	Chart review	Visit preparation and support	Compliance with procedures	Positive effect
Anderson (2017)	Interprofessional Collaboration of Dental Hygiene and Communication Sciences and Disorders Students to Meet Oral Health Needs of Children with Autism	Dental	Autistic children (4)	Cohort study	Visit preparation and support	Compliance with procedures	Positive effect
Broder-Fingert (2016)	A Pilot Study of Autism-Specific Care Plans During Hospital Admission	Inpatient	Autistic children (33) Parents and Caregivers (92)	Case control	Care plan or pathway	Primary: Acceptance and feasibility Secondary: Caregiver Satisfaction	No effect Positive effect
Cagetti (2015)	Dental care protocol based on visual supports for children with autism spectrum disorders	Dental	Autistic children (83)	Cohort study	Visit preparation and support	Compliance with procedures	Positive effect
Cermak (2015)	Sensory adapted dental environments to enhance oral care for children with autism spectrum disorders: A randomized controlled pilot study	Dental	Autistic children (44)	Randomized crossover design	Visit preparation and support	Compliance with procedures	Positive effect
Cervantes (2019)	Sustainability of a Care Pathway for Children and Adolescents with Autism Spectrum Disorder on an Inpatient Psychiatric Service	Psychiatry (Inpatient)	Autistic children (52)	Cross-sectional study	Care plan or pathway	Address problem behaviors	Mixed effect
Chebuhar (2013)	Using Picture Schedules in Medical Settings for Patients With an Autism Spectrum Disorder	Outpatient Specialty	Healthcare providers (8) Parents and Caregivers (9)	Survey research	Visit preparation and support	Primary: Staff satisfaction Secondary: Caregiver Satisfaction	Positive effect Positive effect
Clark (2014)	Implementing UK Autism Policy and National Institute for Health and Care Excellence guidance- assessing the impact of Autism training for frontline staff in community learning disabilities teams	Outpatient Specialty	Healthcare providers (8)	Focus group or other qualitative assessment	Staff education	Acceptance and feasibility	Positive effect
Clark (2019)	Improving Communication Between Health Care Providers, Families, and Children with Autism Spectrum Disorder: The Linked Program	Surgical	Autistic children (31)	Cohort study	Care plan or pathway	Compliance with procedures	Positive effect
Cox (2017)	Establishing motion control in children with autism and intellectual disability: Applications for anatomical and functional MRI	Procedure (Outpatient)	Autistic children (7)	Observational study	Visit preparation and support	Compliance with procedures	Positive effect
Cuvo (2010)	Training children with autism spectrum disorders to be compliant with a physical exam	Primary Care (Outpatient)	Autistic children (6)	Observational study	Visit preparation and support	Compliance with procedures	Positive effect
Donnelly (2021)	Staff Perceptions and Implementation Fidelity of an Autism Spectrum Disorder Care Pathway on a Child/Adolescent General Psychiatric Inpatient Service	Psychiatry (Inpatient)	Healthcare providers (30) Autistic children (28)	Mixed methods	Care plan or pathway	Staff satisfaction Acceptance and Feasibility	Positive effect Mixed effect
Drake (2012)	Evaluation of a coping kit for children with challenging behaviors in a pediatric hospital	Inpatient	Healthcare providers (24)	Survey research	Visit preparation and support	Address problem behaviors	Positive effect

Table 1. (Continued)

Author (Date)	Title	Setting	Participants (N)	Study Design	Intervention Type	Outcome	Outcome Effect
Gabriels (2012)	Improving Psychiatric Hospital Care for Pediatric Patients with Autism Spectrum Disorders and Intellectual Disabilities	Psychiatry (Inpatient)	Autistic children (117)	Chart review	System change	Address problem behaviors	Positive effect
Gupta (2019)	Utilization of a Novel Pathway in a Tertiary Pediatric Hospital to Meet the Sensory Needs of Acutely Ill Pediatric Patients	ED	Parents and caregivers (23)	Mixed methods	Care plan or pathway	Caregiver satisfaction	Positive effect
Hawkins (2019)	Bergamot Aromatherapy for Medical Office-Induced Anxiety Among Children With an Autism Spectrum Disorder: A Randomized, Controlled, Blinded Clinical Trial	Primary Care (Outpatient)	Autistic children (25)	RCT	Visit preparation and support	Address problem behaviors	No effect
Hoang (2023)	Virtual Training of Medical Students to Promote the Comfort and Cooperation of Patients with Neurodevelopmental Disabilities	Educational setting	Healthcare providers (7)	Quasi-experimental	Staff education	Staff knowledge or confidence	Positive effect
Holt (2018)	Parent-reported experience of using a real-time text messaging service for dental appointments for children and young people with autism spectrum conditions: A pilot study	Dental	Parents and caregivers (17)	Survey research	Visit preparation and support	Acceptance and feasibility	Positive effect
Horien (2020)	Low-motion fMRI data can be obtained in pediatric participants undergoing a 60-minute scan protocol	Procedure (Outpatient)	Autistic children (5)	Case control	Visit preparation and support	Compliance with procedures	Positive effect
Isong (2014)	Addressing Dental Fear in Children With Autism Spectrum Disorders: A Randomized Controlled Pilot Study Using Electronic Screen Media	Dental	Autistic children (80)	RCT	Visit preparation and support	Compliance with procedures	Positive effect
Johnson (2014)	Effect of a social script iPad application for children with autism going to imaging	Procedure (Outpatient)	Autistic children (32)	RCT	Visit preparation and support	Address problem behaviors	Positive effect
Johnson (2012)	Children With Developmental Disabilities at a Pediatric Hospital: Staff Education to Prevent and Manage Challenging Behaviors	Inpatient	Healthcare providers (604)	Survey research	Staff education	Staff knowledge or confidence	Positive effect
Kuriakose (2018)	Does an Autism Spectrum Disorder Care Pathway Improve Care for Children and Adolescents with ASD in Inpatient Psychiatric Units?	Psychiatry (Inpatient)	Autistic children (37)	Chart review	Care plan or pathway	Address problem behaviors	Positive effect
Lucarelli (2018)	Development and Evaluation of an Educational Initiative to Improve Hospital Personnel Preparedness to Care for Children with Autism Spectrum Disorder	Outpatient Specialty	Healthcare providers (168)	Survey research	Staff education	Staff knowledge or confidence	Positive effect
Mah (2016)	Visual Schedule System in Dental Care for Patients with Autism: A Pilot Study	Dental	Autistic children (14)	RCT	Visit preparation and support	Compliance with procedures	Positive effect
Mahoney (2023)	Many Hands Working Together: Adapting Hospital Care to Support Autistic Children's Mental Health	Inpatient	Healthcare providers (18)	Survey research	Staff education	Staff knowledge or confidence	Positive effect
Martinez Perez (2023)	Importance of Desensitization for Autistic Children in Dental Practice	Dental	Autistic children (19)	Cohort study	Visit preparation and support	Compliance with procedures	Positive effect

Table 1. (Continued)

Author (Date)	Title	Setting	Participants (N)	Study Design	Intervention Type	Outcome	Outcome Effect
McGonigle (2013)	Development and evaluation of educational materials for pre-hospital and emergency department personnel on the care of patients with autism spectrum disorder	ED	Healthcare providers (110)	Survey research	Staff education	Staff satisfaction	Positive effect
Murshid (2017)	Effectiveness of a preparatory aid in facilitating oral assessment in a group of Saudi children with autism spectrum disorders in Central Saudi Arabia	Dental	Parents and caregivers (40)	Cross-sectional study	Visit preparation and support	Compliance with procedures	Positive effect
Narzisi (2020)	"Mom Let's Go to the Dentist!" Preliminary Feasibility of a Tailored Dental Intervention for Children with Autism Spectrum Disorder in the Italian Public Health Service	Dental	Parents and caregivers (59)	Cohort study	Visit preparation and support	Compliance with procedures	Positive effect
Nelson (2017)	Predicting successful dental examinations for children with autism spectrum disorder in the context of a dental desensitization program	Dental	Autistic children (168)	Chart review	Care plan or pathway	Compliance with procedures	Positive effect
Nicolaidis (2016)	The Development and Evaluation of an Online Healthcare Toolkit for Autistic Adults and their Primary Care Providers	Primary Care (Outpatient)	Healthcare providers (51) Autistic adults (259) Autistic children (45)	Cross-sectional study	Care plan or pathway	Acceptance and feasibility	Positive effect
Nordahl (2008)	Brief report: methods for acquiring structural MRI data in very young children with autism without the use of sedation	Procedure (Outpatient)	Healthcare providers (47)	Mixed methods	Visit preparation and support	Compliance with procedures	Positive effect
Ocanto (2020)	The development and implementation of a training program for pediatric dentistry residents working with patients diagnosed with ASD in a special needs dental clinic	Dental	Healthcare providers (47)	Survey research	Staff education	Staff knowledge or confidence	Positive effect
Orellana (2014)	Training Adults and Children with an Autism Spectrum Disorder to be Compliant with a Clinical Dental Assessment Using a TEACCH-Based Approach. Treatment and Education of Autistic and related Communication-handicapped Children	Dental	Autistic children (72)	Cohort study	Visit preparation and support	Compliance with procedures	Positive effect
Orellana (2019)	Psychoeducational intervention to improve oral assessment in people with autism spectrum disorder, BIO-BIO region, Chile	Dental	Autistic children (82)	Cohort study	Visit preparation and support	Compliance with procedures	Positive effect
Pavlov (2023)	COVID-19 Vaccination Clinic for Individuals With Autism Spectrum Disorder and Related Disorders: Feasibility and Acceptability	Outpatient Specialty	Autistic children and adults (57) Parents and caregivers (40) Healthcare providers (20) Parents and Caregivers (8)	Cohort study	Visit preparation and support	Primary: Compliance with procedures Secondary: Caregiver satisfaction	Positive effect
Pratt (2012)	Ensuring successful admission to hospital for young people with learning difficulties, autism and challenging behavior: a continuous quality improvement and change management program	Inpatient	Healthcare providers (20) Parents and Caregivers (8)	QI	Care plan or pathway	Primary: Staff satisfaction Secondary: Caregiver satisfaction	Positive effect Positive effect



Table 1. (Continued)

Author (Date)	Title	Setting	Participants (N)	Study Design	Intervention Type	Outcome	Outcome Effect
Primeau (2016)	Individuals with autism spectrum disorders have equal success rate but require longer periods of systematic desensitization than control patients to complete ambulatory polysomnography	Procedure (Outpatient)	Autistic children (161)	Cohort study	Visit preparation and support	Compliance with procedures	Positive effect
Sahyoun (2023)	Safety and Efficacy Associated With a Family-Centered Procedural Sedation Protocol for Children With Autism Spectrum Disorder or Developmental Delay	Surgical	Autistic children (43)	Descriptive	Visit preparation and support	Compliance with procedures	Positive effect
Silva (2018)	Impact of a provider training program on the treatment of children with autism spectrum disorder at psychosocial care units in Brazil	Psychiatry (Inpatient)	Healthcare providers (14)	Cohort study	Staff education	Staff knowledge or confidence	Positive effect
Stein Duker (2023)	Sensory Adaptations to Improve Physiological and Behavioral Distress During Dental Visits in Autistic Children: A Randomized Crossover Trial	Dental	Autistic children (162)	RCT	Visit preparation and support	Address problem behaviors	Positive effect
Swartz (2017)	Benefits of an individualized perioperative plan for children with autism spectrum disorder	Surgical	Parents and caregivers (124)	Chart review	Care plan or pathway	Caregiver satisfaction	Positive effect
Szalwinski (2019)	Effects of decreasing inter-session interval duration on graduated exposure treatment during simulated routine dental care	Dental	Autistic adults (3)	Cohort study	Visit preparation and support	Compliance with procedures	Positive effect
Taylor (2019)	Inpatient Psychiatric Treatment of Serious Behavioral Problems in Children with ASD: Specialized Versus General Inpatient Units	Psychiatry (Inpatient)	Autistic children and adults (80)	Cohort study	System change	Address problem behaviors	Positive effect
Thompson (2014)	Improving Management of Patients With Autism Spectrum Disorder Having Scheduled Surgery: Optimizing Practice	Surgical	Autistic children (24)	Mixed methods	Care plan or pathway	Caregiver satisfaction	Positive effect
Whippey (2019)	Enhanced perioperative management of children with autism: a pilot study	Surgical	Autistic children (18)	Observational study	Care plan or pathway	Acceptance and feasibility	Positive effect
Wirtz (2020)	Patient Outcomes Associated With Tailored Hospital Programs for Intellectual Disabilities	Inpatient	Autistic adults (6618)	Chart review	System change	Organizational change	Positive effect
Yost (2019)	Children with Autism Spectrum Disorder Are Able to Maintain Dental Skills: A Two-Year Case Review of Desensitization Treatment	Dental	Autistic children (138)	Chart review	Visit preparation and support	Compliance with procedures	Positive effect

ASD indicates autism spectrum disorder; ED, emergency department; MRI, magnetic resonance imaging; QI, quality improvement; RCT, randomized controlled trial; TEACCH, treatment and education of autistic and related communication handicapped children.



**Table 2.** Study Characteristics N = 49

Variable	Findings	N (%)
<i>Country of study</i>		N = 49
	US	34 (69.4%)
	UK and Europe	6 (12.2%)
	Canada	4 (8.2%)
<i>Setting</i>	Other	5 (10.2%)
		N = 49
	Dental	17 (34.7%)
	Procedural/Surgical	11 (22.4%)
	Psychiatry	6 (12.2%)
	Outpatient Specialty Clinics and Primary Care	7 (14.3%)
	Inpatient pediatrics	5 (10.2%)
<i>Type of Study</i>	Emergency Department	2 (4.1%)
	Medical School	1 (2.0%)
		N = 49
	Descriptive Study (e.g., chart review, cohort studies, etc.)	23 (47%)
	Survey	8 (16.3%)
	Randomized trial or crossover design	6 (12.2%)
	Mixed Methods	4 (8.2%)
	Quasi-Experimental	1 (2.0%)
	Cross-sectional study	3 (6.1%)
	Case-Control	2 (4.1%)
<i>Type of Intervention</i>	QI	1 (2.0%)
	Focus Group or Qualitative assessment	1 (2.0%)
		N = 49
	Visit preparation and support	26 (53.0%)
	Comprehensive care plan or pathway	12 (24.5%)
	Staff education and training	8 (16.3%)
	System change	3 (6.1%)

QI indicates quality improvement.

**Table 3.** Study Subjects and Outcomes

Subjects	N = 55 (%)	
	Autistic Children and/or Adults	33 (60%)
	Health care providers/staff/students	13 (23.6%)
	Parents and caregivers	9 (16.4%)
<i>Number of Subjects</i>		N = 55 (%)
	Studies with ≤ 20	17 (31%)
	Studies 21–100	27 (49%)
	Studies between 101 and 200	8 (14.5%)
<i>Primary and Secondary Outcomes</i>	Studies > 200	3 (5.5%)
		N = 55 (%)
	Compliance with procedures	22 (40.0%)
	Address problem behaviors	8 (14.5%)
	Parent satisfaction	7 (12.7%)
	Staff knowledge, confidence and/or attitudes	7 (12.7%)
	Acceptance and feasibility of intervention	6 (10.9%)
	Staff satisfaction	4 (7.3%)
<i>Study Effect</i>	Organizational change	1 (1.8%)
		N = 55 (%)
	Positive	51 (92.7%)
	Mixed	2 (3.6%)
	No effect	2 (3.6%)

(N = 55 as six studies had a secondary set of subjects and outcomes).

autistic individuals, one in an inpatient medical setting and two in an inpatient psychiatric setting.

### SUBJECTS

While a total of 49 papers were included, six studies assessed more than one outcome that employed a different methodology or subject population (N = 55) (Table 3). The subjects of the majority of studies were autistic children and/or adults (N = 33, 60%) with the remainder

of studies distributed between the subjects as health care providers (N = 13, 23.6%) or parents and caregivers (N = 9, 16.4%). A total of eight studies had a sample size greater than 100 (14.5%) and 17 studies (31%) had sample sizes of less than 20 participants. In one study, hospital discharge records of 6618 children across five hospitals were assessed. Twelve studies included individuals with developmental delay/intellectual disability in addition to autism.

## STUDY TYPE

The most common study methodology was descriptive, (N=23, 47%) including observational studies, chart reviews and cohort studies, followed by survey research (N=8, 16.3%). Mixed method, case-control, quality improvement, qualitative or focus group and cross-sectional study methodology were each utilized in four or fewer studies. There were a total of 6 studies that were either randomized controlled trials (RCTs) or utilized a crossover design (N=6, 12.2%).

## OUTCOMES

The most common outcome assessed was procedural compliance (N=22, 40.0%) as a binary variable (yes/no). Of the 22 studies that assessed procedural compliance, 15 were completed in dental settings (68.2%) and three (15%) were related to completing MRI scans. Some studies also measured the number of steps needed to complete a procedure or the time to completion.

Remaining outcomes assessed in eight or less studies included reduction in problem behaviors, acceptance and feasibility of the intervention, staff and parent satisfaction, changes in staff knowledge, confidence and attitudes, and large organizational change. Behaviors, staff and parent satisfaction, and changes in knowledge, confidence and attitudes were often measured via researcher-created tools ("Behavior Observation Tool") or pre-post course evaluation surveys and, rarely, by utilizing existing standardized measures.

A total of five studies assessed the impact of interventions on length of stay and the use of restraints. Three of these studies were in psychiatric settings (60%) and two were conducted at the same psychiatric setting. The study with the largest number of participants reported that autistic children with a high level of medical illness severity (determined by the admission severity of illness score, ASOI), who were treated at hospitals without tailored programs for children with autism and other neurodevelopmental disorders, had 38% longer stays, 42% total higher costs, and 10% higher costs per day than children without autism who were treated at those hospitals.

All six RCTs or crossover trials were conducted in a pediatric outpatient setting, four in the dental setting (66.7%), one in a radiology setting evaluating the use of a visual schedule/support system or electronic media to assist autistic children in completing visits, and one in an outpatient setting evaluating the use of aromatherapy to improve medical exam anxiety. All assessed an intervention that provided visit preparation and support, with two being electronic visual supports, one being a visual support schedule not in electronic format, two being sensory adaptations to the environment, and one being aromatherapy. Most of the studies involved less than 50 individuals (range 14–44), with two studies enrolling 80 and 162 autistic children, respectively. Half of the studies' outcome was compliance with a procedure, while the other half assessed reduction of problem behaviors. Five of six reported a positive effect. The aromatherapy

intervention did not have an effect on patient anxiety. All six RCTs attempted to objectively measure patient distress via either heart rate and blood pressure (three studies) or electrodermal conductance (three studies). Additionally, five RCTs utilized at least one standardized caregiver or provider completed rating scale to quantify behavior, stress, and/or anxiety, though no single scale was consistently used across studies.

## DISCUSSION

This scoping review investigated interventions designed to optimize the care of people with autism in health care settings. The large number of articles excluded over the course of the review process suggests that, while accommodating and supporting autistic individuals in health care settings is of high need and relevance, rigorous methodologies to evaluate these interventions is lacking. Smaller numbers of studies were identified in the two most recent reviews by Kouo<sup>6</sup> in 2019 who identified 23 relevant papers and Walsh<sup>10</sup> in 2020 finding 31 manuscripts. Of note, when comparing our results to these reviews, only nine papers within either review overlapped with those in our study and only two papers were included in all three reviews. This may reflect different definitions of the study population, exclusion of certain settings, the concept being searched or the context/driving questions for the scoping review. Additionally, six papers that were included within our review were published after the Walsh review was completed and seven were included after the completion of the Kouo review. Even with this variation, findings were similar in terms of the breadth of available research.

Overall, included studies had limited methodological rigor and small sample sizes with only six studies using a randomized controlled trial or crossover design. Kouo similarly found only 12 of 23 studies reviewed utilized a research design, while the remainder of the articles simply described recommendations.<sup>6</sup> Walsh and colleagues<sup>10</sup> also found most studies were quasi-randomized controlled trials or pre-posttest knowledge assessments (51.6%) and single-subject research such as changing criterion design (32.3%).

The majority of studies were conducted in dental or procedural settings, with limited representation from inpatient hospital or emergency settings. Notably, the current mental health crisis has led to increased rates of behavioral health concerns, requiring a higher level of care among autistic individuals resulting in boarding in emergency departments and pediatric inpatient units while awaiting psychiatric placement.<sup>77</sup> This amplifies the urgency for our call to address supports for this population in the inpatient and emergency room setting. Very few evaluated interventions that required an inter-professional or inter-departmental approach,<sup>20,45</sup> with only one study assessing organizational change as an outcome.<sup>75</sup>

While variables such as satisfaction or acceptability may be appropriate for preliminary, proof of concept studies, they are often insufficient evidence of the efficacy

of an intervention. In our review, a few analyses utilized behavioral or emotional rating scales to quantify distress in patients. However, the tools chosen were more likely to be investigator designed rather than standardized instruments and no standard rating scale was used consistently across studies.<sup>45,49,50,54,55,61,63</sup> Of note, all of the studies using RCT or crossover design attempted to quantify behavioral or emotional distress via physiologic measures, either via electrodermal conductance or heart rate and blood pressure.<sup>36,46,50,52,54,69</sup> Objective measures such as time to completion of an exam or procedure, use of restraints, use of anxiolysis, and/or length of stay, were assessed in only six studies, and three of those were in an inpatient psychiatric setting.<sup>20,37,43,50,59</sup>

There were some significant omissions from most included studies. Only two studies included autistic individuals and family members in the development and evaluation of interventions.<sup>21,69</sup> While a child's chronological age may have restricted access to obtaining some patient feedback, the opinions and experiences of autistic individuals and their families in developing interventions was absent. No study examined the racial and ethnic characteristics of the study population or related potential inequities in delivering a study intervention. We find this relevant given the findings from nine studies in a recent scoping review looking specifically at health disparities in autistic individuals, which suggested race as an important factor in decreased access to and quality of health care early in life.<sup>78</sup> However, interventions targeting improved access and health care quality have not yet begun to consider the effectiveness of these interventions in the groups of individuals most at risk for adverse outcomes.

There were some limitations to our study. We utilized scoping review methodology, which is a relatively new concept that may have less consistency in data collection and analysis than longer standing systematic review methodologies. Given that scoping reviews are useful when seeking to ask broader questions and/or to summarize a literature base that may demonstrate significant heterogeneity, we felt this methodology was most appropriate to address our purpose. Some key articles may have been missed using our search strategy and the combination of key words chosen. We sought to mitigate this by working with a certified medical librarian with expertise in this area. Finally, we acknowledge publication bias towards publication of positive results.

In conclusion, while there is evidence for potentially effective interventions to accommodate autistic patients in health care settings, there remains a lack of outcome measures to support their broad application at this time. This scoping review uncovers a need to conduct large-scale, multi-site, well-designed intervention implementation research in this area. Researchers and clinicians developing interventions need a shared framework for conducting implementation research that clearly defines subjects/populations, accounts for the range and spectrum of autistic traits and abilities, and highlights appropriate objectives and quantifiable outcome measures. Results of training initiatives must go beyond assessing acquired

knowledge, satisfaction, and confidence and assess the impact on care and health. Autistic individuals and families must be partners in developing and testing interventions, and we encourage racial and ethnic diversity in this research to ensure that recommended accommodations are culturally informed and applicable across diversity in all aspects. Lastly, we endorse a research agenda that targets improving care for autistic individuals at an institutional level including enhanced interprofessional communication, care pathways, interdisciplinary teams and greater provider with specialized training to provide care. These will be harder to evaluate but likely essential to best outcomes for autistic patients.

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## AUTHOR CONTRIBUTIONS

Drs Holly K. Harris and Carol Weitzman conceptualized and designed the study. They completed the review, including screening article abstracts, reviewing full text, extracting data from articles, and meeting regularly as a team to discuss any disagreements occurring during the two-reviewer process. They drafted the manuscript. Dr. Laura Weissman conceptualized and designed the study. She completed the review, including screening article abstracts, reviewing full text, extracting data from articles, and meeting regularly as a team to discuss any disagreements occurring during the two-reviewer process. Ms. Chloe Rotman conducted the literature search and exported literature to Covidence for author review. Drs. Eron Y. Friedlaender, Ann M. Neumeyer, Sarabeth Broder-Fingert, Sarah J. Spence, and Mr. Alexander J. Friedman and Ms. Shari Krauss completed the review, including screening article abstracts, reviewing full text, extracting data from articles, and meeting regularly as a team to discuss any disagreements occurring during the two-reviewer process. All authors critically reviewed the manuscript and approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

## DECLARATION OF COMPETING INTEREST

This statement is to declare that the authors have no potential conflicts of interest relevant to this article.

## SUPPORTING MATERIAL

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.acap.2023.11.006](https://doi.org/10.1016/j.acap.2023.11.006).

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