

Toward Practice Advancement in Emergency Care for Children With Autism Spectrum Disorder

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abstract

BACKGROUND AND OBJECTIVE: There is increasing recognition that children with autism spectrum disorder (ASD) experience challenges in busy clinical environments such as the emergency department (ED). ASD may heighten adverse responses to sensory input or transitions, which can impose greater difficulty for a child to cope with situational demands. These problems can be amplified in the ED because of its busy and unpredictable nature, wait times, and bodily care. There is little literature documenting ED-based needs of children with ASD to inform clinical guidelines. The objective was to identify stakeholder perspectives in determining clinical priorities and recommendations to guide ED service delivery for children with ASD.

METHODS: After qualitative interviews with children, parents, and health care providers conducted in a previous phase of this study, focus groups were convened with parents of children with ASD, ED clinicians, and ED administrators (total $n = 60$). Qualitative data were analyzed based on an interpretive description approach.

RESULTS: Participants identified the ED and its delivery of care as insufficient to meet the unique needs of children with ASD. The following clinical priorities were identified: ASD-focused preparedness for ED procedures and processes, wait time management, proactive strategies for sedation and restraint, child-focused support, health care provider capacity building, post-ED follow-up resources, and transition planning to adult care. Heightened child- and family-centered care were strongly recommended.

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DOI: 10.1542/peds.2015-2851S

Accepted for publication Nov 9, 2015

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

To cite: Nicholas DB, Zwaigenbaum L, Muskat B, et al. Toward Practice Advancement in Emergency Care for Children With Autism Spectrum Disorder. *Pediatrics*. 2016;137(s2):e20152851S

Children with autism spectrum disorder (ASD) have unique needs necessitating additional accommodation when accessing health care. Health and health care experiences are affected by ASD features and comorbid conditions such as communication deficits, hypersensitivities and hyposensitivities, complex behaviors, and mental health problems. Relative to peers, there is a higher occurrence of chronic problems such as sleep disturbance and psychopathology among youth with high-functioning ASD, risking well-being and functioning.¹ The multiplicity of problems may compromise a child's ability to fully participate in and benefit from health interventions.² It is important that health care providers accommodate diagnostic features, comorbidities, and other secondary needs as presented by a child with ASD to ensure optimal assessment, care experience, and outcome.

Care providers specifically in the emergency department (ED) must address and balance the medical needs of a wide array of urgent clinical presentations. Yet it is recognized that ED attendance is more common for children with ASD than nonaffected peers,³ and with an estimated prevalence rate of 1 in 68 children,⁴ health service providers increasingly need to be prepared for the challenges of this cohort of service users. The interplay of factors potentially presented by a child with ASD when seeking treatment in an ED may compound the care that is needed. If this need is not addressed sufficiently, misguided treatment or undertreatment may result, potentially yielding suboptimal outcomes. A recent survey of parents of hospitalized children with ASD highlights the need for health care providers to gain sufficient knowledge about the communication and sensory needs of a child with ASD when developing her or his

care plan.⁵ The literature identifies multiple barriers to this care given the difficulties that some children with ASD experience, such as hypersensitivity to stimuli including sound, touch, and transition.⁶⁻⁹

Communication barriers are reported to potentially heighten anxiety for the child and increase misunderstanding between others involved in care.⁶ Some children may be unable to communicate their level of pain in ways that are discernible by service providers and parents.⁶ Parents report sensitivities that can affect functioning and care experience.⁵ Thus, there are a range of factors that merit consideration for individual care planning and heighten caution in assessing ED or hospital presentation of a child with ASD.⁵

Environmental challenges are increasingly recognized because the ED is intensive and unpredictable and therefore may trigger adverse responses. Examples of challenging ED features for children with ASD (and other children) are wait times, abrupt communication, physical examination, and invasive procedures involving imposed bodily touch and physical discomfort.^{10,11} One study attributes sensory overload to common environmental features of the ED such as intense noise and movement, bright lighting, and a crowded environment.¹² Parents of children with ASD identify procedural and behavioral elements of care that result in negative experiences, and in some cases these experiences can have lingering impacts on the child, including exacerbations of physical and mental health issues.⁷

Recommendations call for greater ASD training for ED teams, with the goal of improving care trajectories and optimizing ED experiences and outcomes.¹³ ASD screening has been advanced as a means to guide care. For instance, Pratt et al¹⁴ implemented a hospital-wide preadmission checklist that

screened for learning disability and ASD. Completed by parents, the checklist screened for communication, sensory, and behavioral considerations. The checklist was positively evaluated by parents and health care providers.¹⁴ Unfortunately, other resources targeting ASD-related ED practice were not found in the literature. Although studies increasingly advocate for greater sensitivity in ASD-related ED care, there is a dearth of guidance for clinicians and administrators.

To address this gap, we conducted a study examining the experiences of ED care from the perspectives of children with ASD, their parents, and ED health care providers. This article reflects a substudy of this larger project by reporting findings from focus groups held with key stakeholders consisting of parents, clinicians, and administrators in the ED. The purpose of this substudy was to examine and prioritize emergent findings for ED practice and program development. Research questions addressed were: 'What are the perceived gaps and needs in ED care for children with ASD?' and 'What resources and supports are needed to optimize ED care for children with ASD?'.

METHODS

Parents of children with ASD ($n = 16$), ED health care providers ($n = 37$), and ED administrative leaders (eg, nursing manager, medical director) ($n = 7$) were recruited from the EDs of 2 Autism Speaks Autism Treatment Network (ATN) sites: the Stollery Children's Hospital, Edmonton and the Hospital for Sick Children, Toronto. Both hospitals are pediatric tertiary-level hospitals in diverse geographic regions. Participants previously interviewed about ASD-related ED practices (within an earlier phase of the study) took part in focus groups, as did additional

TABLE 1 Position or Discipline of Participants by Focus Group Session

	Group 1	Group 2	Group 3	Group 4	Group 5	Group 6	Total
Parent			2		14		16
Administrator		1				5	6
Family-centered care council member						1	1
Health care trainee	1				1		2
Health care provider							
Nurse		2		2			4
Occupational therapist			2		1		3
Physician	8		5	1		1	15
Psychometrist					3		3
Researcher	1		2		3		6
Social worker		1	1				2
Speech language pathologist			1				1
Undisclosed			1				1
Total	10	4	14	3	22	7	60

participants who had extensive experience in the topic under study. E-mailed or verbal invitations to participate were distributed to an open list of ATN stakeholders, comprising the local ATN, including parents receiving care or support through providers within the ATN. If willing, participants were enrolled and informed consent was obtained. Institutional ethics review board approval was obtained from each of the host sites.

Participants were first provided with a summary of key interview findings from an earlier phase of the study in which in-depth interviews were conducted with 29 families of children with ASD treated in a pediatric ED (including 4 children with ASD) and 22 ED health care providers. These findings, reported in detail in forthcoming articles by this team, have identified challenges to and facilitators of ED care. Reflecting on these findings, focus group participants were invited to expound on the resonance and relevance of these earlier interview findings and identify priorities for advancing ED practice. Sessions were recorded and extensive field notes were taken by research assistants in preparation for analysis.

The analysis was guided by interpretive description, a recent method that examines the “surface

of words and events” rather than generating in-depth analysis.^{15(p. 336)} This qualitative research approach is ideal when interpretation is not laden with deep theoretical underpinnings or the need for critical contextual analysis. The aim herein was to collect data targeted at practicality and programmatic guidance for ED service delivery.

Transcripts were subjected to line-by-line coding, categorization of codes, and the determination of themes. Analysis was supported by qualitative analytic software (N-Vivo 10). Negative case analysis was used to explicitly search the data for exceptions to emerging codes, and the research team regularly reviewed emerging findings.^{16,17} Data saturation was achieved.

Six focus group sessions ($n = 60$, mean = 10 participants per session) were held between February and July 2014. Given the substantial geographic distance between sites, groups did not contain members from different sites. Table 1 identifies participant affiliation and health care discipline represented in each focus group session.

RESULTS

Participants advocated for care that targeted the needs of children with ASD. Emergent priorities reflected

frequently and poignantly identified care considerations relative to ASD, as outlined below.

Preparedness for ED Care Procedures and Processes

Participants stated that children with ASD often have more severe challenges in the ED than peers. Identifying and proactively addressing children’s unique sensitivities within care adaptation were cited as priorities to improved care. A standardized method was recommended for identifying ASD-related needs, collected in as streamlined and innocuous ways as possible. For instance, a brief standardized checklist at registration was identified as a possible means to efficiently collect information for care planning, such as, “a care plan that is a 1-page recipe card with brief [information]. . . . It’s helpful to have that knowledge.” Participants suggested that a screening tool could identify special needs, care accommodation requirements, communication style, potential triggers, and strategies to optimize care. Infusing parental guidance in screening was thought to honor parents’ expertise about their child and offer strategies based on parental observations of the child in high-stress environments such as the ED. A participant advised, “You can photocopy it and put it on the chart.

It may not say everything, but [it] says some of their stuff and I think that helps.”

Wait Time Management

Children with ASD were described to increasingly decompensate and emotionally struggle as unstructured waiting in the ED ensued. Although a challenge for many children, this was viewed as more debilitating for many children with ASD, particularly if behavioral or emotional regulation was fragile and ED waiting time became lengthy. Because of the typically unexpected and unplanned nature of an ED visit, parents often lacked opportunity to bring compensatory distraction items for their child.

Both parents and health care providers recognized that the management of wait times in the ED is a complex issue, particularly given other pressing issues in the treatment of children with acute and urgent needs and the management of an unpredictable work flow. One parent stated, “8 hour wait times are very difficult. The iPad battery doesn’t last that long. Also not knowing if you can give your child a snack or things like that.” Possibilities for initial patient triage involved a range of factors including acuity and disability-related functioning. To proactively manage waiting, alternative quiet spaces outside common (often boisterous) waiting areas were recommended, with embedded distraction items such as art supplies and computer or video games. One parent recommended an alternative to on-site waiting: “Sometimes you go to restaurants that have long waits and they give you that page system so that you can disappear until you’re going to get closer to the time you might be called. And I just think how wonderful that would be because it would enable you to get your child out of that [ED] environment to somewhere they’re comfortable and safe and only be

in that setting for as long as you absolutely have to be.”

Proactive Sedation and Restraint Strategies

Participants recommended engaging the child and parent in determining effective ways to proactively manage sedation and restraint. Restraint was deemed warranted only if absolutely needed. Examples of areas for consideration were the use of a mask for sedation, gentle touch in the aim of supporting a child to remain calm or still (as needed in a procedure), and an invitation for family guidance on how to optimally tailor the procedure. Participants stressed the importance of honoring parents’ advice, given their key role in the life of their child and their resultant understanding about care sensitivities and previously effective and noneffective strategies. One parent described seeing her child physically restrained as “a very, very traumatic experience for me and for him. . . . It just seemed to me that there had to be a better way to do it. I understand that they’re in a hurry, but this is a little boy.” Another added, “The sedation was an issue for [the child]. It was . . . a scary situation [for him] because I don’t think they realize how many people you have to go through. . . . We interacted with eight or nine different people before he was actually put under.”

Child-Focused Support

Child-oriented supports were recommended, including access to child-friendly resources. From the perspective of several health care providers, child life specialists offered an important role in attending to children’s developmental needs and teaching staff about techniques for working with children with ASD. As an example, a participant stated, “The best interactions I’ve ever had with kids with autism doing painful procedures, Child Life has always been involved with them.”

Emerging resources for a range of developmental levels and areas of interest were invited. These included sensory-rich items, quiet spaces, calming strategies, clarity in signage to increase orientation to time and place, areas in which to move, options and places for breaks, and accessible areas for acquiring snacks.

Capacity Building

ASD capacity building in the ED was recommended through education to trainees, ongoing professional development, sharing of resources by specialized care teams, and the development of toolkits. There was a reported need for health care provider skill development in proactive interventions for aggressive behavior associated with ASD: “My biggest fear is the kid that’s more aggressive,” and, “Having some education about de-escalation would be very helpful.” Skill development was recommended in de-escalation and assisting parents in crisis.

Primary care providers were also identified as potential recipients of community education because their practices were viewed to be hubs of community care for children with ASD. These primary care providers were also viewed and valued as potential sources of education for families in terms of preparing for the ED.

Follow-up Resources

Participants stated that substantial resource gaps in ASD support and related health service systems impede appropriate ED follow-up, thereby leaving children with ASD at heightened risk for ED readmission or other crisis events. System-wide resource development relative to follow-up care for children with ASD was expected to positively affect outcomes after an ED visit. As indicated by 1 participant, “If the role of coming to the ED is to access the specialist, that’s part of the sort of ‘broken down-ness’ of

the system, where, changing the ED doesn't actually get to the root of the problem. . . . We need to figure out a different way to get the neurologist to that child, which does not require them to come to [the ED]. . . . [Them coming to the ED] makes it more complicated." To that end, the formation of strategic planning teams was posited as a means to identify and address issues and priorities, with potential representation of ED staff, ASD service providers, administrators, pediatric and adult care representatives, and families.

Transition Planning to Adult Care

Participants noted that care delivery in nonpediatric facilities substantially differs from that of pediatric EDs. For instance, parents may not be as welcomed or engaged in care in nonpediatric facilities because of a heightened orientation to individual patient privacy and a presumption of adult agency (unless court-ordered guardianship orders are in place), yet parental advocacy may still be needed. One health care provider said, "With kids who have a number of chronic issues . . . [the staff] have to do a transition process. . . . I don't think [that] kids with autism . . . are being followed in the same way [with] transition [to adult care]." Health care providers believed that a care plan should be developed with families that could be carried from pediatric to adult care, based on the developmental functioning of the youth with ASD. Such a care plan could address care issues and potentially mitigate elements of difficulty associated with acute or emergent care for the youth or young adult with ASD. A health care provider stated, "What is nice . . . is if they have a care plan and are going (to) the adult side. . . . I do approach adults differently than I approach children . . . unless [I] know if they have a particular diagnosis and that family is with them and that family is the primary caregiver."

DISCUSSION

Concern over current ASD care practices in the ED prompted recommendations for ED practice and program development. Overall, participants strongly sought practices and processes of care that were attuned to the needs of children with ASD. This invited capacity building among ED health care providers and the broader system of care.

Education and practice development were recommended, which could be addressed by strategically targeting the learning needs of key stakeholders. For instance, family education could guide children and parents about what can be planned and anticipated in an ED visit. For health care providers, education could be presented in didactic sessions, print and toolkit materials, interdisciplinary simulated care scenarios, video or Web media productions, and specialist presentation in rounds. Partnering with internal champions who are committed to building ASD capacity in the ED may exponentially advance informational uptake.

The identified need for capacity building in this study was consistent with earlier research,¹³ including recommendations for staff training about the care of acutely agitated patients.¹⁰ Of note, however, earlier studies have largely drawn on expert opinion. In contrast, the findings from the current study more broadly represent distinct stakeholder perspectives including parents of children with ASD, interdisciplinary health care professionals, and administrators.

Planning for ASD capacity building in EDs invites multiple steps: reviewing and developing best approaches, trialing strategies, establishing feasibility, obtaining resource requirements, developing curricula, and conducting evaluation. Recommendations from this study both corroborate and build on the

literature that has suggested tools for care improvement. For instance, Pratt et al's introduction of a checklist at hospital preadmission identified a way to screen for communication, sensory, and behavior "trigger points"^{14(p.795)} among pediatric patients. These findings are advanced by the current study, which posits the potential need for a parent-informed screening mechanism specifically for ED care planning. Participants relayed challenges on how such a tool could be implemented, citing caution in constraining document length and not prolonging the triage process. Suggested means for implementation and communication favored the development of an electronic format to ease barriers of transferability and access among staff. Participants also suggested emulating and building on strategies for other patient groups who frequently access ED care and similarly have complex needs, whereby binders in the ED contain relevant care information for staff.

Increased proactivity in systems of ED care offers a pathway for improved ED experiences and outcomes for children with ASD. Such reconfiguring of care has resource implications that must be considered in hospital and ED program planning; however, potential savings may offset costs through health issues being proactively addressed. For instance, heightened ASD competence in care may prevent children from being triggered into meltdowns and the need for greater resource infusion.

Study Limitations

The generalizability of these findings to other ED populations is limited by the qualitative method of this study. Sampling sites were pediatric hospitals located only in Canada; however, it is important to note that sites were in disparate regions with diverse health service systems. Despite substantial efforts to recruit broadly within the original sample of interviewed families (which

ultimately informed these focus groups), the initial sample ultimately consisted only of families in which a child with ASD had accessed the ED for a physical health problem rather than a primarily mental health concern. This limitation reflected random case identification in participating EDs during data collection; however, we speculate that mental health emergencies among children and youth with ASD may entail additional complexity related to patient and family experience, care processes, and follow-up resource considerations. Questions emerge in terms of such potentially unique care experiences and outcomes for that particular cohort of children and their families, which invite additional study. Notwithstanding this identified gap in child and family representation within the original interview

sample, the sample of this substudy, that is, the focus groups, included participants with ED experience related to both mental health and physical health concerns as the primary reason for ED attendance.

Implications for Research

Health service research is recommended to ascertain reasons for and proactive responses to the use of the ED by children with ASD. Assessment of ED-related considerations is warranted, such as accuracy of diagnosis, time to treat, positive and negative care occurrences, and ED readmission and followup. Studies must reflect diverse ASD samples (eg, ASD functioning, physical vs mental health-based issues, child age, cultural background). Assessment of the long-term outcome of ED care is also recommended, such as impacts

on subsequent health care utilization, family stress, and community care access.

CONCLUSIONS

The input of service users, health care providers, and administrators invites a stronger focus on ASD, family-centered care, and capacity building in the ED. It is acknowledged that ASD confounds children's emergency care needs and heightens risk for poor ED experiences. The results from this study offer guidance for ASD-based ED care, and suggest that advancing such strategies is indeed worthy of pursuit.

ABBREVIATIONS

ASD: autism spectrum disorder
ATN: Autism Treatment Network
ED: emergency department

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FINANCIAL DISCLOSURE: Dr Zwaigenbaum has received grant funding from the Canadian Institutes of Health Research, NeuroDevNet, Women's and Children's Health Research Institute, and has a grant under review by the Azreieli Foundation and Brain Canada. He was also site principal investigator on a biomarker study funded by SynaptDx but did not receive any personal compensation. The other authors have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: Supported by cooperative agreement UA3 MC11054 through the US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Research Program to the Massachusetts General Hospital. Conducted through the Autism Speaks Autism Treatment Network, serving as the Autism Intervention Research Network on Physical Health. The views expressed in this article do not necessarily reflect the views of Autism Speaks, Inc or HRSA. Study design, fieldwork, writing of the manuscript, and decision to submit for publication reflected the work of the authorship team. Funds were received from this agreement to cover expenses related to this project. Dr Newton is supported by a New Investigator salary award from the Canadian Institutes of Health Research. Dr Zwaigenbaum is supported by the Stollery Children's Hospital Foundation Chair in Autism. Ms Greenblatt and Mr Kilmer declare that their involvement as study coordinators was included in the approved study funds, and they received payment from these funds through their respective institutions.

POTENTIAL CONFLICT OF INTEREST: Dr Zwaigenbaum has received grant funding from the Canadian Institutes of Health Research, NeuroDevNet, Women's and Children's Health Research Institute, and SynaptDx and has a grant under review by the Azreieli Foundation and Brain Canada. The other authors have indicated they have no potential conflicts of interest to disclose.

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Pediatrics 2016;137;S205

DOI: 10.1542/peds.2015-2851S

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