School Nurse’s Role in Managing Autism Spectrum Disorder in the School Setting

MICHIGAN SCHOOL NURSE GUIDELINES AND RESOURCES

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Foreword

These guidelines contain recommendations for current best practices for the health service topic addressed. They have been reviewed by the School Nurse Practice Subcommittee of the Michigan Statewide School Nurse Task Force as a means to provide consistent and safe care to the students. Specific laws and regulations that direct school nursing practice or other health services are identified in the guidelines. There is no guarantee that the use of guidance in this document will lead to any particular result or outcome. The information in this document was researched in May, 2016.

Purpose

This document will provide guidelines and resources for the school nurse’s role in managing autism spectrum disorder (ASD) in the school setting.

Overview

Autism spectrum disorder (ASD) is a group of developmental disabilities that can cause significant social, communication and behavioral challenges as well as place substantial strain on family members (Siu & the U.S. Preventive Services Task Force, 2016). The Centers for Disease Control and Prevention (CDC) (2016a) provides information about the new standardized criteria from the American Psychiatric Association’s Diagnostic and Statistical Manual, Fifth Edition (DSM-5) to help diagnose ASD. The new criteria have eliminated the previously separated categories of Asperger Syndrome, Child Disintegrative Disorder and Pervasive Developmental Disorder now consolidated under the term Autism Spectrum Disorder. The new criteria have two versus three domains: 1) Persistent deficits in social communication and social interaction across multiple contexts and 2) Restricted, repetitive patterns of behavior, interests, or activities. The CDC (2016b) reported the following information about ASD. About 1 in 68 children has been identified with autism spectrum disorder according to estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. ASD occurs in all racial, ethnic, and socioeconomic groups and is about 4.5 times more common among boys (1 in 42) than among girls (1 in 189). Studies in Asia, Europe, and North America have identified individuals with ASD with an average prevalence between 1% and 2%. About 1 in 6 children in the United States had a developmental disability in 2006-2008, ranging from mild disabilities such as speech and language impairments to serious developmental disabilities, such as intellectual disabilities, cerebral palsy, and autism (CDC, 2016b).

The Centers for Disease Control and Prevention (2016c) indicated that “children or adults with ASD might:

- Not point at objects to show interest (for example, not point at an airplane flying over).
- Not look at objects when another person points at them.
- Have trouble relating to others or not have an interest in other people at all.
- Avoid eye contact and want to be alone.
- Have trouble understanding other people’s feelings or talking about their own feelings.
- Prefer not to be held or cuddled, or might cuddle only when they want to.
- Appear to be unaware when people talk to them, but respond to other sounds.
MICHIGAN ASSOCIATION OF SCHOOL NURSES – SCHOOL NURSES ROLE IN MANAGING AUTISM SPECTRUM DISORDER IN THE SCHOOL SETTING

- Be very interested in people, but not know how to talk, play, or relate to them.
- Repeat or echo words or phrases said to them, or repeat words or phrases in place of normal language.
- Have trouble expressing their needs using typical words or motions.
- Not play “pretend” games (for example, not pretend to “feed” a doll).
- Repeat actions over and over again.
- Have trouble adapting when there is a change in routine.
- Have unusual reactions to the way things smell, taste, look, feel, or sound.
- Lose skills they once had (for example, stop saying words they were using)” (2nd para).

Studies have also found children with ASD may have difficulty with generalization of skills and motor limitations, such as, poor motor coordination, balance, hypotonia and apraxia (Rutkowski & Brimer, 2014). Children with ASD often struggle with sleep (Jolly, 2015; McGuire et al., 2016). Chandler, Howlin, Simonoff, O’Sullivan, Tseng, Kennedy, Charman, & Baird (2015) discovered significant comorbid emotional and behavioral problems with autism can be detected as early as age 4-5 years. Greenlee, Mosley, Shui, Veenstra-VanderWeele, & Gotham, K.O. (2016) found co-occurring depression is a particularly common problem in high-functioning older children with ASD.

There may be many different factors that make a child more likely to have an ASD, including environmental, biologic and genetic factors. Siblings of children who have ASD are at greater risk for having ASD as well as children born to older parents. ASD tends to occur more often in people who have certain genetic or chromosomal conditions, such as, fragile X syndrome or tuberous sclerosis (CDC, 2016c).

Comprehensive developmental evaluation is a concern for children with ASD. Early diagnosis and intervention can have a significant positive impact on the developmental outcomes of children with ASD (Zwaigenbaum et al., 2015). Evidence supports that behavioral signs can be detected in the second year of life. The CDC (2016a) reported that less than half of children with ASD received a comprehensive developmental evaluation by age 3 years. The lag between first concern and first comprehensive developmental evaluation may affect when children are being diagnosed and connected to needed services. The American Academy of Pediatrics (AAP) recommends screening at 18 and 24 months and when screening results are concerning, children should receive a comprehensive developmental evaluation from a general or developmental pediatrician, child neurologist, or child psychiatrist (AAP Council on Children with Disabilities, 2016; CDC, 2016d). The evaluation can be obtained privately or through Part C (ages 0-less than 3 years) or Part B (ages 3-21 years) programs of the Individuals with Disabilities Education Act (U.S. Department of Health and Human Services [USDHHS]/CDC (2016).

Evidence links early treatment to improved outcomes (USDHHS/CDC, 2016). Benvides, Carretta & Lane (2016) compared children with ASD to other children with special health care needs and found a greater percentage of children with ASD were reported to need therapy than other children with special health care needs (1.4 times more likely to report an unmet need for therapy). Occupational therapy, physical therapy and speech therapy were among the most used services by children in educational and medical services (Benvides et al., 2016). Chiri and Warfield (2012) found the most significant factor impacting access to services reported by families of children with ASD relative to other children with special health care needs was provider knowledge and skill. Cheak-Zamora & Farmer (2015) found family-centered
The care and care coordination components of the medical home were drivers of improved access to specialized services.

The CDC (2016e) also discusses the importance of early intervention and behavioral communication approaches as critical therapy. Michigan has the autism insurance reform and the Medicaid benefit for behavioral intervention for children meeting Medicaid and ASD eligibility. Behavioral intervention can significantly reduce problem behaviors in addition to increasing skill acquisition. More information about Applied Behavioral Analysis (ABA) can be found at http://www.cdc.gov/ncbddd/autism/treatment.html.

The economic burden associated with ASD is substantial. Lavelle et al., (2014) found higher levels of health care office visits and prescription drug use compared with children without ASD. ASD was also associated with higher health care costs. Benevides et al., (2016) found families of children with ASD have high out-of-pocket expenses for care.

**Michigan Data**

The Michigan Department of Health and Human Services [MDHHS] (2016) reported that in the 2015-2016 school year, 18,746 students diagnosed with ASD were enrolled in Michigan schools (Michigan Department of Education [MDE]). Approximately 50,000 individuals living in Michigan have ASD.

**Legal Framework for Managing Autism Spectrum Disorder in Schools**

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<td>34 CFR Part 300 Individuals with Disabilities Act of 1997 (IDEA)</td>
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<td><strong>Michigan Law</strong></td>
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Michigan's Autism Insurance Reform legislation (PA 99 and PA 100 of 2012) went into effect on October 15, 2012. For-profit, commercial, HMO, and non-profit health insurance companies regulated by the state of Michigan are mandated to provide an autism benefit to its insured members covering services related to the diagnosis and treatment of autism spectrum disorders (ASD) through 18 years of age.

An informational bulletin published in July 2014 clarifying Medicaid coverage of services for children with ASD under the federal Medicaid Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit.
Public health provides the foundation for the specialty practice of school nursing and is one of the five principles of the Framework for 21st Century School Nursing Practice (National Association of School Nurses (NASN), 2016). Key tenets and responsibilities of public health practiced by school nurses include surveillance, outreach, population-based care, levels of prevention, social determinants of health and health equity (Maughan, Bobo, Butler, Schantz, & Schoessler, 2015; NASN, 2016). Care Coordination is also one of the principles of the Framework for the 21st Century School Nursing Practice. School nurses provide care coordination when they facilitate student and family preferences and needs by organizing and sharing information among persons (NASN, 2016). Case management, collaborative communication, direct care, student care plans and transition planning are practice components of school nursing. Both the public health and care coordination principles provide guidance and a framework for the role of the school nurse when managing students with ASD in the school setting.

The NASN Position Statement “Section 504 and Individuals with Disabilities Education Improvement Act – The Role of the School Nurse” includes identifying children who may need special education or health-related services, collaboratively assessing the child’s functional and physical health status, and assisting parents to remove health-related barriers to learning as roles of the school nurse that can be applied to students with ASD (NASN, 2013).

School Nurse’s Role

Recommendations for Practice

Public Health

Surveillance

1. School nurses need to be aware of the students diagnosed with ASD in the population they serve (Minchella & Preti, 2011).

2. Vision and hearing screening and follow-up care are important to minimize sensory deficits (Taliaferro & Resha, 2016).

Population-Based Care

1. Advocate for policies that support early assessment and treatment for ASD children.

2. Know the local, state and national resources for children with autism (Strunk, 2009).
Social Determinants of Health

Black and Hispanic children are less likely to be identified with ASD. Those that are identified with ASD receive comprehensive developmental evaluations later than white children who are identified with ASD (CDC, 2016e). The CDC (2016e) reported that it was possible that black and Hispanic children faced socioeconomic or other barriers resulting in a lack of or delayed access to evaluation, diagnosis, and services.

School nurses need to understand cultural beliefs and differences to facilitate communication among culturally diverse parents/caregivers of children with ASD (Luong, Yoder, & Canham, 2009; Strunk, 2009). Luong, Yoder & Canham (2009) advocated for information to be printed in different languages specific to the demographics of the community. The CDC (2016f) provides free materials about learning developmental milestones that are offered in different languages. The materials can be retrieved from http://www.cdc.gov/ncbddd/actearly/freematerials.html.

Care Coordination

Case management

1. Provide family education, support and resources (Engelke, Guttu & Warren, 2009).

   - The Center for Parent Information and Resources (CPIR) provides information and facts for parents at http://www.parentcenterhub.org/nichcy-resources/. Information for parents can also be found at the National Institute for Neurologic Disorders and Stroke http://www.ninds.nih.gov/disorders/autism/autism.htm).

   - The MDHHS provides information and resources to support families/caregivers and professionals servicing individuals with autism spectrum disorder. More information can be found at: http://www.michigan.gov/autism.

   - Statewide Autism and Resources Training (START) (https://www.gvsu.edu/autismcenter/). This is a program out of Grand Valley State University funded by the Michigan Department of Education. START has a basis in Positive Behavior Interventions and Supports (PBIS) and marked 15 years in 2016.

   - Michigan Alliance for Families (MAF) (http://www.michiganallianceforfamilies.org/), is also funded by a MDE (and partial federal) grant which provides information, education and support for parents whose children receive or eligible to receive special education services or early intervention services. The alliance has parent mentors regionally across Michigan that can provide information to families on the special education process and answer questions. They also provide excellent online resources.

2. Provide community referrals for care providers, support groups, behavior counseling, educational programs, respite care, primary health care providers, and crisis intervention (Minchella & Preti, 2011).

3. Help families with sleep problems their children experience (McGuire et al., 2016). The Autism Treatment Network provides a toolkit for parents to promote sleep in children with autism that can be retrieved at: https://www.autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/sleep-tool-kit

Collaborative Communication

1. Proper communication among school staff, community providers and parents is key to successfully working with a student with ASD (McIntosh, Thomas, & Brattain, 2016; Minchella & Preti, 2011; Strunk, 2009).

2. Establish a communication and information-sharing system between the school system and health care system (Anderson, 2009).

Direct Care

Students with ASD may need additional support and strategies to facilitate communication and ensure a safe environment. The following approaches may assist school nurses as they provide direct care to students.

- Keep the environment simple and highly structured (Selekman, Diefenbeck & Guthrie, 2013).
- Decrease environmental stimulation by keeping lights low, decreasing noise levels (Jolly, 2015).
- Provide the student’s favorite video or music when resting or waiting (Minchella & Preti, 2011).
- Be concrete and specific when making requests using clear and literal language in a calm, quiet voice (Jolly, 2015; Minchella & Preti, 2011; Selekman et al., 2013).
- Develop predictable routines for medication administration. Picture schedules may be helpful. (Selekman et al., 2013; Minchella & Preti, 2011).
- Consider offering a reward when medication is taken to establish a pattern of positive reinforcement as many children with ASD respond well to reward systems (Jolly, 2015).
- Consider sign language, gestures, vocalizations, and picture symbols in the health office if verbal communication is affected. Students with ASD may have stronger visual than auditory processing skills. (Selekman et al., 2013; Minchella & Preti, 2011).
- Use minimally invasive procedures, for example, temporal, ear or infrared thermometers (Minchella & Preti, 2011).
- Learn words that are familiar to the child (Ely, Chen-Lim, Carpenter, Wallhauser & Friedlaender, 2016).
- Use of nonverbal pain scales, such as the Faces, Legs, Activity, Cry, and Consolability (FLACC) scale has been recommended for children with cognitive impairments (Jolly, 2015). Information about the FLACC scale can be retrieved at: http://www.nhpc.org/flacc-scores. Ely, Chen-Lim, Carpenter, Wallhauser & Friedlaender (2016) found locating pain was a favored technique to help describe pain in children with ASD.
• Obtain the student’s baseline presentation from classroom staff and parents that includes communication methods, pain awareness, triggers, and stressors that cause anxiety or aggression. (Jolly, 2015; Minchella & Preti, 2011). Determine what works best to soothe the child at home and determine de-escalation techniques for periods of increasing agitation (Jolly, 2015).
• Work with the family to identify if the child is particularly agitated by touch, sound, smell, sight, tastes or food (Jolly, 2015).
• Assess whether the child is at risk of doing harm to self or others. Assess for a history of tantrums, meltdowns, rages; property destruction; aggression to others (McGuire et al., 2016).
• Remain informed of the student’s behavior intervention plan (Jolly, 2015).
• Document care provided to the student and family (Lyerla, 2013).

Student Care Plans

1. Develop Individualized Health Care Plans (IHP) when appropriate to provide a safe school environment (Minchella & Preti, 2011; Engelke et al., 2009).

2. Lyons (2012) offered a template for a school assessment form for students with special health care needs. Information retrieved for the assessment form can be used to develop an IHP.

3. Consider convening a 504 or Individual Education Program meeting to discuss challenges and the student’s limitations for field trips, such as the need for any health service, frequency of service, level of care required, and storage of medications (Erwin, Clark, & Mercer, 2014).

3. Communicate with teachers assigned to teach the PE curriculum so they understand that students with ASD will need help from adults or other students, acting as peer models, to interpret the social cues and social environment in their class (Rutkowski & Brimer, 2014).

Transition Planning

1. Plan for transitions and clearly communicate critical information about the child on methods of communication, triggers leading to agitation and anxiety, daily schedule and child preferences during the transition phase (Jolly, 2015; Minchella & Preti, 2011).
Red Flags for Managing Autism Spectrum Disorder in the School Setting

1. Parents of children with autism spectrum disorder are known to experience more stress than parents of children with any other condition. Rivard, Terroux, Parent-Boursier & Mercier (2014) studied parental stress of 118 fathers and 118 mothers and found fathers reported higher stress levels than mothers. The stress levels of both parents were associated with their child’s age, intellectual quotient, severity of autistic symptoms and child’s gender. The authors indicated results of this study showed many parents of children with ASD report levels of stress reaching a clinical threshold.

2. Anderson (2009) conducted a study to document mother’s experiences of the care of their children with special health care needs across health care and educational settings and found that mother’s reported communication with health care providers and schools was difficult and that mothers were overwhelmed with coordinating care for their children.

3. The MDHHS (2016) reported that 65% of parents reported their child with ASD had been bullied (National Autism Association).

References


