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# Caring for Children With Severe Allergies: Establishing Protocols for EpiPens and Other Medical Needs Through Collaborative Practices

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# Caring for Children With Severe Allergies

Establishing Protocols for EpiPens and Other Medical Needs Through Collaborative Practices

#### Will Parnell, Allison Schnur, and Lynn Green

s educators and researchers, throughout our work with young children and families, we authors have cared for children who were prescribed an epinephrine auto-injection device to be used in the case of a severe allergic reaction. However, it wasn't until we actually had to consider using such a device, commonly referred to as an EpiPen—a popular

brand of epinephrine auto-injector—that we realized the care plan for these children was unclear. In many ways, the protocols and care-taking processes for managing severe allergies felt unlike those for many other medical concerns due to the instantaneous lifethreatening nature, immediately needed reactions, and unestablished protocols in our field. Most important,

26 Young Children September 2016

this uncertainty could cause a lack of overall safety for educators, children, and families.

In Allison's class of twenty-four 3- to 5-year-olds at the Helen Gordon Child Development Center at Portland State University in Portland, Oregon, two children suffered from allergies and required EpiPens to be kept on hand. Several times, Allison and her coteacher found themselves in an emergency situation, described below, in which they knew they needed to act quickly, yet neither was sure what to do.

Allison wrote about her experience in her journal:

Only a few months into the school year, my coteacher and I found ourselves in a situation in which we were unsure of the best way to care for a child. Suzanne ate soup containing garbanzo beans, one of the items she was allergic to. As anaphylaxis is serious and life-threatening, we knew that every minute was essential, and we quickly sought support from our colleagues. We didn't know whether Suzanne had actually ingested a garbanzo bean, or if she was exposed to the beans through the soup's broth. Was she allergic to garbanzo beans by ingestion or touch? We asked each other if we should administer the EpiPen right away or only when we saw signs of anaphylaxis. We weren't entirely clear on what her parents would want us to do or if such actions aligned with our own medical training. Fortunately, Suzanne was fine after a dose of Benadryl, and we considered this a learning experience. (Adapted from Allison's journal, October 13)

This alarming moment led us, as classroom teachers, to explore ways to develop procedures and policy for children at risk of anaphylaxis—a serious, lifethreatening allergic reaction—in our program. We interviewed families and school educators to hear more about their experiences, reviewed academic literature from medical and educational journals, and then interpreted those findings as a basis for creating policy and procedures to achieve a safer school. We found ourselves winding through the complex nature of relationship building between educators, children, and families, as we used our research to establish a universal system of procedures, such as consistent signage and storage, as well as written, individualized care documents for each child.

# A need for school policy changes

A review of the literature suggests that allergies among children are on the rise across the country. Murphy writes that "the prevalence of food allergy in children (less than 18 years) in the United States increased by 18% between 1997 and 2007" (2014, 51). With increases like these, familiarity with procedures for using EpiPens will likely become as much a part of early care and education as recognizing and reporting signs of abuse, which is now expected practice.

Procedures for caring for children with EpiPens and other medical concerns appear to not yet be viewed as part of nurturing the whole child in early childhood education. Consequently, related policies and comprehensive professional development are still not commonplace, though they are becoming increasingly available (Oregon Secretary of State 2015). In our research, those interviewed indicated that all educators should have professional development offered by a licensed health professional to recognize the symptoms of anaphylaxis and to use EpiPens. Further, Forster and Bryant (2004) report that many educators and administrators are unaware of children's specific health needs, including knowing whether or not children with allergies have individual health care plans for their epinephrine auto-injector and, if so, where the plans and EpiPens are located. In our experience, this unawareness persists today.

There is a critical need for schools to develop policies and increase awareness around the use of EpiPens. By reporting on the experiences of those in our field and the supporting data, we can bring awareness to the inconsistencies in the care of children's life-threatening medical needs. Additionally, by creating a template for the care of children with life-threatening allergies, we can help prevent emergencies and deaths at schools due to anaphylaxis. We find that providing children and parents with an educational setting that feels safe decreases anxiety about severe allergies. Collaborative approaches to health advocacy support parents, empower educators, and encourage children to become advocates for their own health.

Addressing the emotional concerns of children and families—considering the whole child—is as important as addressing physical needs, and best supports families. Sanagavarapu (2012) reminds us, "In the

September 2016 Young Children 27

case of children, the *effects* are also transferred through parents' stresses and coping ... researchers [and educators] need to adopt a 'bio-psychological perspective' that emphasizes understanding food allergy from both biological and socio-cultural perspectives" (57). Thus, as Sanagavarapu points out, the effects of food allergies on families are not simply physical—children and parents are impacted in many ways, including both economically and socially.

When an entire school community is aware of and using the same system for EpiPens, educators are better informed and provide better care.

Overall, the majority of literature about allergy and EpiPens has emerged from the medical field (Forster & Bryant 2004; Hu, Kerridge, & Kemp 2004). We found few studies on the topic published in education and social science journals. The voices of both parents and educators are underrepresented in the literature. Parents' thoughts were most often included in nonacademic digital news sources, such as blogs, websites, and online newsletters rather than clinically researched sources. Due to this research paucity, it is our aim to authentically listen to parents who have children with severe allergies and give them an important role in their children's safety at school.

# **Transforming questions into action**

Allison reflected on the day she and her coteacher were confronted with an emergency—a student exposed to a food allergen:

After that emotional afternoon in which I faced a decision whether or not to administer a child's EpiPen, my mind returned to all the unanswered questions that arose. In an effort to get answers, I reached out to the parents of the two children with EpiPens in the class. They expressed their anxiety about their children's care in emergency situations and their uncertainty of

the appropriate medical procedures. Multiple teachers and administrators at our center echoed these sentiments. (Adapted from Allison's journal, October 24)

Primarily in response to this incident, Helen Gordon Center staff and administrators spent the following 18 months developing procedures to care for children with EpiPens. We realized these protocols needed to be extended to all children with medical devices (e.g., oxygen readers, inhalers, feeding tubes) or medication that requires educators to take action. Three themes crucial to the care of young children with EpiPens emerged in interviews with parents, educators, and administrators: (1) proximity and storage of EpiPens; (2) individualized care plans for each child requiring an EpiPen; and (3) establishment of a culture of self-advocacy in children with allergies and EpiPens.

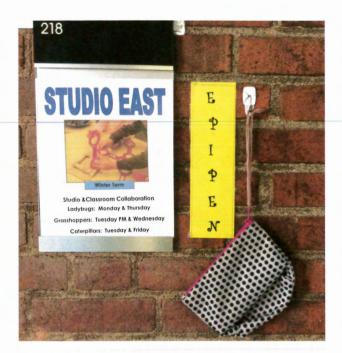
### **Proximity and storage**

Parents, educators, and administrators shared personal experiences in which schools stored EpiPens in locations outside of the classroom, such as the school office or nurse's room, or kept them in classrooms but not quickly accessible. They agreed that EpiPens should travel with a child whenever possible, whether moving from room to room or on field trips. EpiPens must be accessible at all times, traveling either on the child, when age-appropriate, or on an educator.

During interviews, educators and parents emphasized the importance of EpiPens being readily accessible to the school staff, because a matter of seconds can make a difference in saving a life. Cynthia, a parent whose two children have EpiPens for multiple allergies, said her primary request was that their EpiPens travel with each child throughout the day. She questioned the practice of leaving EpiPens in the classroom at all times, and wondered what happened when children played outside or visited other spaces in the school. Cynthia said, "Just the idea that we would put more space and more obstacles between our daughters and something that could save their lives is terrifying."

Educators and administrators echoed Cynthia's concern during their interviews, wondering how many precious seconds might be wasted if an educator had to travel through a building to retrieve an EpiPen. They clarified that close proximity was in the best interest of

28 Young Children September 2016



the school, to ensure the administration of emergency medication to children as quickly as possible (Educator and administrator interviews, February 25 and March 3).

We found that consistency also played a role in the responsible storage of EpiPens. Margaret, an administrator at Helen Gordon Center, explained that once an entire community used the same system, it allowed the whole school to better care for all the children. "The EpiPen system in the school is becoming well known. Everyone recognizes the yellow EpiPen sign—that it means if a child is in that area and they have an EpiPen, it should be on that hook" (Administrator interview, March 3).

Cynthia echoed Margaret's thoughts. She noted that when an entire school community is aware of and using the same system for EpiPens, educators are better informed and provide better care. For example, a substitute teacher will know where to find emergency medication because the consistent schoolwide policy and protocols are explicitly covered in their orientation, handbook, and classroom labeling, so any teacher can quickly step in and aid a teacher from another classroom in an emergency (Parent interview, February 18).

In further consideration of EpiPen storage, teachers and parents noted that clear signage was essential to the system. Signage marking EpiPen storage should be consistent, be similar to that marking automatic defibrillators, and have a visual marker that all adults can recognize.

Some educators and parents had been part of school communities in which EpiPens were stored in locked cupboards or offices, often with only a few adults having the keys to access the locked space. One hundred percent of the educators interviewed felt strongly that EpiPen storage should always remain unlocked—for the same reasons that the auto-injectors should travel with a child—administering epinephrine in a timely manner is crucial and can be lifesaving. Though they shared other recommendations for creating a safe and empowering school environment, their concern about proximity and storage was of the highest importance.

Consequently, all educators in this study successfully stored EpiPens on hooks out of children's reach in classrooms or in auxiliary spaces around the school. Margaret explained how children travel with their EpiPens, a system in which she felt confident: "Wherever the child goes, their pen goes. It is typically up out of reach of children, on a hook in the classroom, or in an auxiliary room, or outside on a field trip in a backpack, so that it is accessible to the caregivers of that child at a moment's notice (Administrator interview, March 3).

### Individual health protocols

Parents and educators interviewed at Helen Gordon Center agreed that individualized plans to follow in case of an emergency needed to be in place for children who have EpiPens or other emergency medications and equipment. Based on the experiences of parents, educators, and administrators, Helen Gordon Center staff developed and implemented Individual Health Protocols (IHPs) as a centerwide practice for each child with life-threatening medical concerns. Each IHP is a detailed, individualized document that clearly identifies a child's allergies or medical concerns, common symptoms, and most important, specifically what to do in each case of exposure or need for care.

Having a consistent system for centerwide IHPs helped parents and educators to feel more confident and empowered in the care of young children with EpiPens and other medical concerns.

Participants in the interviews suggested that Individual Health Protocols be made easily accessible to all those

September 2016 Young Children 29

involved in providing care for a child with health issues. All IHPs are located in consistent, marked locations in each classroom, in the same cabinet as the first aid kits. The center also kept protocols in the main office and in all administrators' offices. Parents and educators agreed that centrally located plans accessible to all staff are essential, and that IHPs be documented in writing. They noted that it is crucial that IHPs be child-specific, and never generic (Administrator interview, March 3).

Written IHPs must clarify when each child might need their EpiPen, based on individual allergies and health history. Barb, a preschool teacher, said, "When you know exactly what needs to be done for a child, and you can see it on the paper and go over it with the family, it's really empowering. When I know what to do in an emergency situation, I can take over. I feel powerful. I can help this child because I know what to do" (Educator interview, February 25). Margaret elaborated on the relief IHPs offered: "We wanted to remove all of the guesswork and give confidence and autonomy to educators so that they can care for children" (Administrator interview, March 3).

When we designed Individual Health Protocols for children, we began with a collaborative meeting. Parents and educators sat down together and identified their questions. Marshall, a parent who volunteered to collaborate in creating the format for Individual Health Protocols, prompted us to think about how a substitute teacher would know how to care for a child if the lead educator was out. Allison's reflective journal

documented the many questions we used as a guide in developing IHPs:

I wonder how our care might vary for each child and how we can further incorporate parent perspective into our care plan. How do we know if a child is allergic by ingestion or by touch? Do we administer the EpiPen right away or only when we witness signs of anaphylaxis? How might we organize all of the emergency health information we have about a child so that our whole team becomes better able to care for them? (Adapted from Allison's journal, October 24)

The entire care team used these questions to create an individualized plan for each child. Our Individual Health Protocols include basic identifying information about each child, the child's previous related symptoms, and most important, an action plan for exposure to specific allergens.

## Fostering self-advocacy

Collaborations such as those on IHPs led the center staff to develop ways to foster a sense of self-advocacy and awareness in children. We found that policies and procedures alone were not enough to fully care for children requiring EpiPens and other emergency medications. Parents and educators emphasized the need for helping even the youngest children develop self-advocacy skills. They shared experiences of multiple methods adults could use to help children identify and verbalize their health needs.

30 Young Children September 2016

Ann, a preschool teacher, believed in the importance of helping young children advocate for all of their bodily needs. She felt that the knowledge and vocalization of children's most basic needs will blossom into selfadvocacy in more serious circumstances, such as with life-threatening allergies. Ann explained how she works with young children to develop this sense. She tells the children, "First, identify what you need for your specific medical concerns, then communicate that to other people" (Educator interview, March 11). As an everyday practice, development of self-advocacy as a skill set can take the shape of expressing a need to use the bathroom, have diaper cream applied, or have more food at meals. Children with allergies and other medical concerns can practice self-advocacy by identifying the foods to which they are allergic or by checking with an adult to be sure their EpiPen is with the adult. When teachers respond in a positive manner, it reinforces children's self-advocacy.

Barb described ways she worked with preschoolers at Helen Gordon Center to ensure they were accountable for having their EpiPen accompany them at all times: "I've asked the children to make sure their EpiPen is with them before they leave the room. So, if they're going from the classroom to the playground, they need to wait for a teacher, and say to the teacher, 'Please make sure you have my EpiPen!'" Barb then helps children build on their self-advocacy skills, and works with them to carry their own EpiPens in preparation for kindergarten (Educator interview, February 25).

### Conclusion

Our schools have many educators and families with ample experience in caring for children with EpiPens. If we actively listen to children and their families, we can learn from their experiences and create environments for the children that are healthier both physically and emotionally. We believe that the recommendations suggested by study participants—proximity and storage, individual health protocols, and self-advocacy—are crucial for providing quality care in which the child is viewed as a whole person. We hope more schools will consider taking similar actions to ensure the safety of children with EpiPens and other medical needs.

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September 2016 Young Children 31