**DRAFT**

# NYC ASSIST NURSE FOCUS GROUP SUMMARIES

## Introduction

On May 8th and May 11th, Michele Israel of Michele Israel Educational Writing & Consulting, conducted two NYC ASSIST focus groups with DOHMH/DOE nurse supervisors, public health advisors, and junior field nurses. The May 8th group (9 participants) represented nurses from Staten Island and Brooklyn; May 11th represented nurses (9 participants) from the Bronx and Queens. Dr. Cheryl Lawrence and Barvina Toledo, both of the DOHMH Office of School Health, co-facilitated.

The purpose of the focus group was to learn from school nurses about their interaction with asthmatic children living in transitional housing. This feedback informs the development of a training to guide nurses in a new intake process, put in place to ensure these children receive appropriate treatment so that they can participate fully – and healthily – in school.

It is important to note that focus group participants had varied levels (very little to substantial) of engagement with children living in transitional housing, depending not only on the borough, but also the district in which schools reside.

While the session's intent was to center on homeless children with asthma, participants also spoke of challenges in providing care to children with asthma in the general student population. In many instances, the obstacles/issues were the same across groups.

## Methodology

Participants responded to seven questions, one of which was centered on a flow chart outlining the new intake process. The other questions focused on the nurses' communication/engagement with parents; interaction with the transitional housing residence staff; relationship with school personnel with regard to supporting the target group; negotiation of challenges encountered once the child receives services (i.e., ongoing parental compliance); actions with regard to families' lack of health insurance; and assistance required to ensure not only a smooth intake process, but also to ensure the ongoing support of children diagnosed with asthma who live in transitional housing.

## Executive Summary

NYC ASSIST was unknown to most of the participants before Dr. Lawrence described the program and the nurses' critical role in its goals and operations. Most attendees were also unfamiliar with the McKinney-Vento Act, and thus were unaware of the scope of rights and services to which children in residential shelters are entitled.

Many attendees did not realize that families in residential shelters have certain benefits, such as health insurance through Medicaid, public assistance, access to Metro cards for travel to medical clinics, a grace period for getting immunizations for children, for example.

While participants spoke to varied circumstances that influence their work with asthmatic children in transitional housing, most highlighted challenges they encounter with parents, from noncompliance to a lack of knowledge about asthma and its impact. Additionally, the group pointed to an overall gap in communication with parents, starting with the shared inability to contact them by phone, to having parents "understand" the importance of using controller vs. maintenance medications.

Many participants were unfamiliar with DOE family assistants (shelter liaisons, caseworkers) and their role in ensuring that homeless children attend public school. Those who had interacted with liaisons shared mixed views about their assistance when it comes to working with parents and their children.

Although many agreed that asthmatic children living in transitional housing often "fall through the cracks," the group offered a variety of existing (those they had undertaken and implemented) and possible strategies for ensuring that the targeted population gets the services it requires. At the core was a solid support team in the school, consisting of key administrative personnel, parent advocate and/or social worker, the pupil accounting secretary and the nurse. The group also underscored the importance of knowing and developing a relationship with shelter liaisons.

**Highlighted Issues and Concerns**

*Medical* Children living with asthma in transitional housing face a number of medical challenges. The following describes those that are outstanding:

- Children are often uprooted and are thus lacking a continuum of care, such as a steady primary care provider. Families, transitioning in and out of shelters, often must find new providers (near the new shelter), and may also have to change insurance plans because new providers/clinics may not accept existing plans. In some cases, specific neighborhoods present limited medical resources and/or good care for asthma, diabetes, and other chronic illnesses.

- Children living in transitional housing do not always come to school (not always due to asthma, but as a result of their lifestyle overall, other chronic illnesses, etc.). It is hard to provide care for these children if they have asthma because they cannot be found in school. Many of these children "fall through the cracks." In some cases, nurses indicated that they do not know that students are in transitional housing until they have a medical issue that requires the nurse's attention.

- Children may end up in the emergency room for treatment because they do not have access to a primary care provider (or because families are hard to reach when a child is having an asthma attack in school). When children do receive a treatment plan, follow up is challenging because parents may not understand the plan, adhere to the plan, return to the doctor, etc. (In some instances, nurse supervisors or school nurses will follow up with the parent and/or the provider.)

- According to participants, parents often tend not to grasp the full scope of asthma's impact on their child, nor recognize the disease's danger. They do not understand treatments and focus on maintenance (but do not understand the limitations of maintenance drugs), i.e., they give the child Albuterol but do not provide controller medication. Sometimes, the children will have nebulizers in school, but not have one in their home (a family may only have one and cannot transport it back and forth). In some cases, children do not even have a "pump." Participants noted that parents may have an interest in learning more about asthma and its effect, like recognizing what triggers their child's asthma. Or, they exhibit a lack of interest in learning more. It also happens that parents do not understand what the doctor/primary care provider explains about asthma.

- Nurses are not always sure whether parents are going to a medical provider. Participants also noted that in some cases, if there is a lapse in insurance, clinics will not provide certain medical services other than immunization. Sometimes, parents will have to change insurance plans if they have moved to another shelter in a new location.

*Engagement with Parents/Families* Participants echoed similar sentiments when describing their interaction with homeless children and their families:

- Parents often do not believe that their child has asthma; parents may have asthma themselves but are "doing fine" with the illness, thus their children can, as well. Students identified as having asthma are identified as thus throughout their school experience (it is on their records), but the parent may disagree with the status, saying that the child has not had asthma in a long while (demonstrating the absence of understanding that asthma is chronic, and therefore not curable.) The challenge is that in order for a "504" to be issued, a doctor must confirm the asthma diagnosis for a child to receive treatment/services. This can only occur if the parent agrees to bring the child to a doctor.

- Some parents are knowledgeable and do understand the essence of asthma care and what their child needs; they are likely to move forward. Other families believe they can handle asthma "in their own way." Some parents do not want their children to become "dependent" on the pump or medication. Parents will also say they understand but choose a different path for treating their child's asthma. There are those who will reach out to the nurse for assistance; i.e. one parent explored with the nurse the cause of her daughter's asthma symptoms at night. One participant noted how one mother would not bring her child's insulin to school, even after the doctor told her this was a necessity. However, the mother's partner would bring the insulin/supplies to the school. Unfortunately, this situation led to a call to ACS (not a desired action, because this indicates parental neglect) and a subsequent meeting among ACS personnel, school staff/administrators, and the mother. This meeting ultimately led to the mother's compliance.

- Parent/family lives are challenging, overwhelming, making it difficult for nurses to engage with parent(s) about their children's health needs. Asthma may not be at the "top of their concerns." Parents may be defensive, especially if it seems to them that the nurse or others "suggest" that they "don't care" about their children. However, there are also instances, according to some participants, where parents appear to be fed up with their children, either because of the illness or other behavioral issues; thus, they are less likely to tend to their children's asthma. Open Airways can empower children to control their asthma and influence their parents. Sometimes this works; sometimes not, depending on the parent.

- It is hard to contact parents. Phone numbers are not consistent; it is not uncommon for nurses to phone many different numbers only to find that they are disconnected/no longer in operation. When nurses send medical notices home, parents might not receive/read them or, if read, not understand them. Thus, parents may not contact the school health office. In some instances, nurses have not been able to reach parents when a child is having an asthma attack at school; sometimes, the child has older siblings in the same school will have the number/contact into of an extended family member -- if not, the child then has to go to the hospital emergency room. Nurses may find alternate numbers on the "blue card," which indicates emergency contact numbers; or, they may call the shelter.

- Sometimes parents will not come to the hospital if the child has been admitted due to issues with asthma..

- One participant acknowledged an overall level of denial among parents/families when it comes to grasping and dealing with chronic disease in general. Another substantiated this via a cultural reference, stating that in the Black community, families tend to handle illnesses themselves. In

this case, the parent is aware of a family history of a chronic disease, like asthma, but that it is in some ways a "family secret" that is not divulged, and thus the asthma (and other chronic disease) is not treated.

- Sometimes, parents will not complete the school residency form because they are living in transitional housing and may be ashamed. Thus, nurses cannot identify those children who are living in transitional housing, which includes "doubling up" ( families that are temporarily living in the homes of family/friends). In some cases, this living situation will not be reported; parents will provide an older or different address.

- Several participants noted how they will reach out to school personnel (the principal, parent advocate, social worker, guidance counselor) to intervene when they are unable to contact and/or work with parents/families.

*Shelter/Nurse Relationship* As noted earlier, most participants were not aware of the family assistant. However, in some cases, where nurses did have relationships with family assistants, they found them to be "uncooperative" and "not forthcoming" with assistance, for example, not going to a family's room to locate a parent when the child needed care at school. Also, some participants indicated that the family assistants were difficult to contact. One participant explained that she has gone to the shelter to interact with the family assistant. Participants also noted that they do not know which shelters are near the schools, let alone the contact person at shelters they are familiar with.

*Other concerns* Participants noted other issues/challenges they encounter, such as:

- When a child has to be admitted to the hospital emergency room, there is a disruption in school staffing, as a teacher has to accompany the child to the hospital if the parent is unreachable. This can be upsetting to a principal. Also, if 911 is called, the school is noted for this call; several 911 calls merit negative attention in school reports.

- Middle schools students living in transitional shelters are particularly hard to track. They are often absent, thought not always due to asthma-related illness.

- Agency nurses are common in challenged schools; they are temporary and, according to participants, not always consistent or on top of student needs, paperwork, etc., especially because they tend to rotate. An agency nurse can be in a school over a longer period of time, but that is not standard.

- Large schools with many students can overwhelm nurses, especially if the student population presents multiple needs. It is not uncommon in a large school for nurses to have over 300 "walk-ins" a month.

- Several participants expressed concerns about the time required to complete paperwork, enter information into the database, etc.

*Suggestions for the Process: What Works or Could Work* Participants shared strategies that do or could enhance support for serving children with asthma living in transitional housing.

*What Seems to Work*

- **CRITICAL:** Establishing a support network/team in the school; this can involve working with the guidance counselor, having the principal intervene when there might be parental noncompliance; setting up a three-way meeting with the nurse, the guidance counselor, and the principal; work with parent coordinator to run health workshops (by external providers or the nurse) for parents, advertised through flyers

- Partnering with a neighboring hospital that can provide services, such as a doctor who will come to the school to examine/treat children.

- Meeting with parents after school or during open school nights (parents will come if they are alerted to students' academic status, i.e., at risk for not being promoted)

- Developing a strong, working with relationship with the "pupil accounting" secretary, who is responsible for registering students and maintaining paperwork that reflects, among other things, residency and medical status.

- Knowing and working with the shelter liaison (this was indicated once in the focus groups; otherwise, this is not typically the case).

*What Might/Could Work*

- Have shelter liaisons call the school nurse to let them know that a child in transitional housing is in the school and/or coming to the nurse for medical needs

- Put a "note" on admission/transfer/discharge form whether student is in transitional housing.

- Offer parent asthma education sessions for parents. (If offered, they should run not only in the morning, but also in the evening so that working parents can attend.)

- Have children be seen by DOHMH doctors on school premises (with parental consent).

- Meet with the shelter liaison (nurse goes to the shelter, liaison visits the nurse at school, have a "greet and meet" gathering that brings together nurses and shelter liaisons from a school district/region).

- Develop/provide a directory of all shelters in a district/region with a list of family assistants (names, contact information, etc.)

**Recommendations**

The following are broad preliminary recommendations with regard to the proposed training of field nurses and nurse supervisors. The training:

- Should spell out NYC ASSIST, the requirements of the revised intake process, the new forms/questionnaires, and the McKinney-Vento Act. Within that should be clear connections to the nurses' roles and how they can assist (rather than focus on what is expected of them). The nurses should feel comfortable with the new processes/paperwork, and feel empowered to provide services to the target population.

- Might engage participants in a problem-solving scenario where they are required to establish relationships (especially with the family assistants)/processes that will help them help the child/family. This would also involve applying certain communication and conflict resolution skills, recognizing the "circle of collaboration" a nurse might build, and identifying/drawing from resources.

- Provide opportunities to learn from (work with?) actual family assistants what their roles are, how they partner/would like to partner with nurses, how they can assist, etc. (Ideally, family assistants would be part of the training and have real roles in the problem-solving task.)

- View/read about/hear about collaborative models that ensure the health of the targeted children. For example, what schools/nurses/shelters do, in fact, have a working, coordinated relationship?

As the nurse supervisor does not work directly with the target population, the training should offer them opportunities to brainstorm and design ways to: help nurses build collaborative relationships and create programs/services within a region that can, for example, educate parents in transitional housing about asthma; coach nurses as they work through the process, etc.