



# Children with Chronic Illness from Multicultural Families:

## Challenges and Solutions for Successful Medical Management via Health Literacy

By Sandra B. Jones & Stephanie E. Jones

**// There is a direct impact on improved well-being, self – determination, and participation in health care...while reducing health care cost for the family, the more the family increases their health literacy. //**

**P**romoting self- management in children from multicultural families, with chronic illnesses, can be difficult for both the parents and the children. In many homes children from diverse cultures and religious beliefs, educational level, customs, languages, traditions, and family values, self-manage their chronic illness, improperly use medications which can ultimately increase their risk of illness, injury, and unfortunately death. Increasing numbers of children, from multicultural backgrounds, are managing chronic illnesses

such as obesity, diabetes, attention deficit disorders, depression, anxiety disorders, bipolar, heart disease, high cholesterol, or hypertension, and sickle cell disease, independently. Several of these diseases were unheard of in children 20-40 years ago. Currently children are developing diseases that were previously seen in middle aged adults; high blood pressure, high cholesterol, fatty livers, and type2 diabetes. The scope of children, from diverse cultural backgrounds, who are managing their chronic illnesses, the cost of chronic illnesses, and how health

literacy is as one of the key strategies for parents and children who are self managing their chronic illness, will be discussed in this article.

### Scope of chronic illnesses in Children

The rate of chronic diseases in children today has doubled in the past two decades. In twenty years, children are now engaged in medical problems that their grandparents are also combating. In analyzing studies in the American Medical Association, according to a 2010 study, some estimates suggest that 26% of children now suffer from a long-term health problem. The study further suggests more than half the children in their study have some type of chronic illnesses, an illness that limits their activities and abilities, or requires special medication and equipment. According to the American Academy of Pediatrics, around 1 in 10 children have asthma, 1 in 5 adolescents aged 9 to 17 struggle with mental illness, such as depression or anxiety, and unfortunately 80% go untreated. Many of these children suffering from the chronic illnesses are from vulnerable populations, such as African Americans, Hispanics, American Indians, and Asian Americans. Some populations are impacted more from specific chronic illnesses than others. In viewing the National Medical Association journal studies, asthma affects African Americans disproportionately.

### Cost of chronic illnesses

First Lady Michelle Obama has been instrumental in creating awareness and identifying strategies to combat one chronic illness—childhood obesity. In one of her nationwide speeches, she addressed the cost of chronic illnesses such as childhood obesity, which creates childhood medical problems, inadvertently causing parents to become less efficient at work. In the ten cities with the highest childhood obesity rates, of which Georgia is ranked number one, the direct cost connected with obesity and obesity related diseases are roughly \$50 million per 100,000 residents. If these ten cities just cut their obesity rates down in the national average, all added up they combine to save nearly \$500 million in health care cost.

### Health Literacy

Health literacy is the ability to read, communicate, and use information in health care either in the home or a medical facility. Low literacy may affect safety,

compliance with medical regimes, diet, use of medications and medical equipment, quality of care, outcomes, and costs of medical care for 25-50% of US adults and children.

Low health literacy in the United States impacts approximately 80 million adults (36%). However, the rates of low health literacy are higher in some segments of subgroups in the population such as minorities, individuals who have not completed high school, populations that are ESOL (English Second Language), people living in poverty, children who may have missed substantial time from school, and children who are recent immigrants to the United States.

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The problem also lies in the approximate 2/3 of 8<sup>th</sup> and 12<sup>th</sup> graders who read below grade level<sup>1</sup>. This low literacy compounds itself with children practicing self-management and parents of children who are also functioning at low literacy.

Health literacy is a low risk/cost/ easy way to ensure the many children who are self- managing their chronic illnesses to lower risk. Many children are self managing their chronic illnesses with prescribed and/or over the counter medications, information on the internet, television, smart phones, and peers, but not with a professionally trained individuals.

As the number of children, from multicultural families, who are diagnosed with a chronic illness increases, it is time to empower their desire for independence and shift “responsible thinking,” transitioning into better accurate engagement and confidence with today health care providers and the health care system. This can be facilitated with skills in health literacy.

The parent is the most major influence that provides support, love, communication, education, and values, for interactions. Children in many ways learn the importance of diet, health, medical

care, and the relationship with health care providers, through interacting with parents.

A family is where a child begins to understand the value of health and compliance with medical regimes to support optimal health and curative factors.

A family is also where the children may begin to learn and hear medical terms and become educated about various illnesses. The family unknowingly may set the stage to define medical terms and medical regimes.

There is a direct impact on improved well-being, self-determination, and participation in health care, while reducing inappropriate health care utilization, medications, medical regimes, and health care cost for the family, the more the family increases their health literacy.

### **Bridging the Gap of Health Literacy and Self Management in Multicultural Families**

There are many strategies parents can use to positively impact the outcomes in managing their chronic illnesses that are directly tied to health literacy:

- **Recognize the cognitive ability of the child who is self managing their chronic illnesses.** Many times health terms and health information is written at a much higher level than the general public is able to decipher. Many health information brochures and pamphlets are written at the high school and college level. Therefore, it is important to dedicate time to make sure the child understands what the health information means in their personal cognitive learning styles and terms.
- **Use methods to explain health information in terms or ways that are understandable to the children.** For example, use pictures, drawings, as a means to ensure a greater understanding of the health terms, such as during teachable moments at the dinner table.
- **Meet the child at their readiness learning level.** This means sometimes there is a lot of information to comprehend at one time. As the family sits down to discuss the various health terms, be aware of the child comfort and confidence level in understanding the

information shared at that time and assess their readiness to learn more.

- **Utilize community partners, such as pharmacists and the school nurses.** These health care providers are important to support successful self-management of children with chronic illnesses. Many times pharmacists and school nurses can be instrumental in providing explanations to help educate youth about their medications, side effects from medications, usage of medical equipment, and other tools to support self management of a chronic illnesses.
- **Encourage your child to ask questions of their health care provider.** By asking the health care provider questions, this gives the child some element of independence, ownership in their health care needs, participation in the care of their bodies, and a sense of self-esteem in being knowledgeable and confident about their self-management.

In summary, there are many variables that impact the success of children to self-manage their chronic illnesses successfully. Health literacy is the one variable that contributes to the successful outcome in the self-management of chronic illnesses immediately controllable in their home. Parents and children from multicultural backgrounds can impact cost and self management by incorporating health literacy practices.

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<sup>1</sup> National Association of State Boards of Education, "From State Policy to Classroom Practice: Improving Literacy Instruction for all Students", The NASBE Adolescent Literacy Network, April 2007.