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UNIVERSITY OF SAN DIEGO

Hahn School of Nursing and Health Science

DOCTOR OF NURSING PRACTICE

**Improving Care for Children and Adolescents with Down Syndrome in the Military  
Health System**

by

Katherine B. Arrogante

A Doctor of Nursing Practice Portfolio presented to the

FACULTY OF THE HAHN SCHOOL OF NURSING AND HEALTH SCIENCE

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DOCTOR OF NURSING PRACTICE

May 2023

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LCDR Alison M. Schurman, DNP, PNP-BC, FNP-C, PMHS, Clinical Mentor

**Documentation of Mastery of DNP Program Outcomes**

## **Final Manuscript**

# **Improving Care for Children and Adolescents with Down Syndrome in the Military Health System**

Katherine B. Arrogante

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### **Author Note**

This evidence-based practice change project would not have been possible without the support, guidance, and dedication of Dr. Martha G. Fuller, PhD, and Dr. Alison M. Schurman, DNP

## Abstract

*Background:* Down syndrome (DS) is the most common chromosomal disorder worldwide. In the United States, DS occurs in one out of every 700 births. Children with DS have an increased risk of developing serious health conditions. In the military health system, children with DS face many barriers such as frequent relocations and poor access to specialty care. Primary care providers (PCPs) do not consistently follow published guidelines for health supervision.

*Purpose:* This project aims to improve the care for pediatric patients with DS in the military health system by increasing the knowledge and confidence of PCPs.

*Methodology:* An educational program on the 2022 American Academy of Pediatrics (AAP) – “Health Supervision for Children and Adolescents with Down Syndrome” guidelines was presented to PCPs at a military treatment facility (MTF). Education included accessing available resources for DS-specific care within the military health system. An anonymous pre- and post-test assessed the providers’ knowledge of DS management.

*Results:* After implementation of this training session, there was a 49% increase on a measure of the providers’ knowledge of and confidence in using the AAP’s health supervision guidelines for DS and accessing available resources for DS-specific care at the MTF.

*Conclusions:* PCPs play an important role in caring for pediatric patients with DS. Provider education on guidelines and the provision of military DS-specific resources can improve outcomes.

*Implications:* Combining provider education on health supervision guidelines with available resources is a cost-effective intervention that can be used in other military treatment facilities.

### **Description of the Clinical Problem**

Down syndrome (DS) is a genetic condition that typically occurs due to the presence of an extra copy of chromosome 21 (Akhtar & Bokhari, 2021) and is the most common chromosomal disorder diagnosed worldwide (Sothirasan et al., 2022). In the United States, approximately 6,000 babies are born each year with DS, which is about one out of every 700 births (Centers for Disease Control and Prevention [CDC], 2022).

Many children with DS have coexisting medical conditions such as congenital heart defects (CHD), hearing loss, obstructive sleep apnea (OSA), otitis media, eye complications, atlantoaxial instability, thyroid disease, and hematologic disorders (Bull et al., 2022). Additionally, children with DS can have a varying degree of intellectual disabilities (Bull et al., 2022). The most common physical features in children with DS include hypotonia, epicanthal folds, flat nasal bridge, upward-slanting palpebral fissures, small ears, excessive skin at the nape of the neck, a single transverse palmar crease, and wide spacing between the first and second toes (Bull et al., 2022).

Children with DS have an increased risk of developing serious health conditions throughout their lifespan (Mengoni & Redman, 2019). They also require high levels of support and therapy due to an increased risk of multiple health and developmental issues in early childhood (Mengoni & Redman, 2019). Therefore, it is crucial to identify these health conditions as early as possible and closely monitor their development (Mengoni & Redman, 2019).

In the military health system (MHS), children of military service members qualify for healthcare coverage through TRICARE, which is a military health insurance program designed for service members and their dependents that provide access to healthcare services in both military and civilian treatment facilities (Seshadri et al., 2019). Even though military families can

receive care from military treatment facilities (MTFs) and civilian facilities, they possess a unique set of circumstances that may challenge their access to health care (Seshadri et al., 2019). According to Hero et al. (2022), approximately two million children under 18 years of age receive healthcare coverage through the TRICARE network. However, children with special health care needs who are covered under TRICARE experience many challenges when it comes to accessing health care (Hero et al., 2022).

Primary care providers (PCPs) play an important role in caring for pediatric patients with DS (Bull et al., 2022). The American Academy of Pediatrics (AAP) recently published updated health supervision guidelines for DS to provide guidance and support for PCPs in the care and management of children with DS (Bull et al., 2022). The AAP health supervision guidelines for DS also aim to improve the long-term outcomes for children with DS through provider awareness and early identification of co-occurring health problems (Mengoni & Redman, 2019). According to Santoro et al. (2018), health care providers do not consistently follow the published AAP health supervision guidelines for DS. Additionally, the literature reveals that health care providers lack the knowledge and training to effectively support families of children with DS (Mengoni & Redman, 2019).

### **Description of the Project**

This evidence-based practice change was an educational intervention that aimed to improve care for pediatric patients with DS by educating health care providers about new guidelines and available resources for management of DS in the pediatric and family medicine primary care settings.

### **Evidence-Based Practice Model**

The Johns Hopkins Nursing Evidence-based Practice Model and Guidelines (JH-NEBP) “integrates the best available scientific evidence with the best available experiential (patient and practitioner) evidence, considers internal and external influences on practice, and encourages critical thinking in the judicious application of such evidence to care of the individual patient, patient population, or system” (Melnyk & Fineout-Overholt, 2019, p. 413). The JH-NEBP Model begins with an inquiry about best practices related to a particular problem and/or a specific patient population (Melnyk & Fineout-Overholt, 2019). This inquiry leads to the core method of the JH-NEBP Model, which is the practice question, evidence, and translation (PET) process (Melnyk & Fineout-Overholt, 2019). By utilizing the PET process, it provides a systematic approach for identifying clinical practice questions that lack evidence-based research, evaluating the existing research, and implementing the best evidence into practice (Melnyk & Fineout-Overholt, 2019). The evidence-based practice project identified that PCPs lack knowledge and training on DS management and are therefore not consistently following the recommended health supervision guidelines for DS. There is current evidence that shows increasing provider knowledge and awareness of the published health supervision guidelines for DS can help improve long-term outcomes and quality of life for children and adolescents with DS (Mengoni & Redman, 2019). For this project, the JH-NEBP Model provided the framework for implementing the current research on increasing the PCPs knowledge and confidence on DS management and translating it in the pediatric primary care and family medicine setting using the PET process (Melnyk & Fineout-Overholt, 2019).



## Synthesis of the Evidence

A literature review was conducted to find evidence to support the educational intervention method of the project to assess provider knowledge and confidence of DS management. Included was a review of evidence to support the importance of provider education on using the AAP's updated clinical practice guidelines for the health supervision of children and adolescents with DS. The following databases were used as search engines: Cumulative Index of Nursing and Allied Health Literature (CINAHL) and PubMed. The following keywords were used: "down syndrome AND pediatrics", "tricare AND pediatrics", "down syndrome AND pediatric guidelines", "down syndrome AND pediatrics AND medical costs", "pre- and post-test AND effectiveness AND medical students", and "down syndrome knowledge AND pre- and post-test." The filters used in the search engines include *free full text, English, published between 2016 – 2022*.

*Down syndrome AND pediatrics* yielded 219 results, 15 of which were saved for further review. *Tricare AND pediatrics* produced 24 results, and 3 articles were saved for review. *Down syndrome AND pediatric guidelines* yielded 15 results, 4 of which were saved. *Down syndrome AND pediatrics AND medical costs* produced 26 results, and 2 articles were saved. *Pre- and post-test AND effectiveness and medical students* yielded 32 results, of which 2 articles were saved. *Down syndrome knowledge AND pre- and post-test* produced 14 articles, of which 0 articles were saved for review. After narrowing the results based on relevance of article content, 15 articles were selected for use. Additionally, an exhaustive search was conducted for a valid and reliable screening tool to measure provider knowledge on DS management without success.

## **Down Syndrome**

The evidence shows that over the last few decades, the life expectancy of individuals with DS has dramatically increased due to improved medical care and psychosocial support (Valentini et al., 2021). However, individuals with DS have an increased risk of developing numerous health complications throughout their lifespan, which many problems may present at birth or in early childhood (Mengoni & Redman, 2019). Some of the common medical conditions seen in children with DS include congenital heart defects (CHD), hearing loss, vision problems, and obstructive sleep apnea (Valentini et al., 2021). For instance, CHD is one of the leading causes of morbidity and mortality in children with DS, especially within the first two years of life (Akhtar et al., 2022). According to Akhtar et al. (2022), the incidence of CHD in babies born with DS is nearly 50%, with the most common cardiac defects being atrioventricular septal defect and ventricular septal defect. Porter et al. (2022) also mentions that hearing loss occurs in approximately 80% of children with DS, which can significantly affect communication, learning, and social development. Thus, early identification and intervention is crucial to prevent any long-term sequelae to this already vulnerable population (Mengoni & Redman, 2018).

In 2022, the AAP published a new update on the recommended clinical practice guidelines for the management of children and adolescents with DS, to help providers determine appropriate screening, referrals, and age-specific anticipatory guidance (Bull et al., 2022). These guidelines aim to improve care and quality of life for children with DS (Hsieh et al., 2019). In a study by Williams et al. (2017), the authors reveal that children with DS are not receiving the recommended health care services. Another study shows that health care providers are not consistently following the published health supervision guidelines for DS (Mengoni & Redman, 2019).

## **Military Medicine**

The literature discusses that children in military families who receive health insurance through TRICARE experience many barriers, such as frequent relocations, increasingly complex health care needs, and a lack of access to specialty care (Seshadri et al., 2019). In addition, a prior survey data from military families with children under the TRICARE network indicate that some of the most difficult challenges military families faced were access to care for children with special health care needs and frequent relocations (Hero et al., 2022). On average, military service members and their families are required to relocate every two to three years (Seshadri et al., 2019). Frequent relocations can affect the health care needs, quality of care, and availability of support networks, especially for children with complex medical conditions (Hero et al., 2022).

Therefore, it is crucial to address these gaps within the MTFs to help assess barriers to achieving adequate healthcare access, particularly for children in military families with complex health care needs (Seshadri et al., 2019).

## **Knowledge, Attitudes, and Behaviors**

There is currently no validated screening tool available to measure health care provider DS specific knowledge and confidence. Pre- and post-tests are often used to measure knowledge, attitudes and practices as a way to determine effectiveness of educational presentations related to other conditions. For instance, Wahlen et al. (2020) performed a study on the impact of a one-hour lecture to medical students on specific health care needs of adolescents in the lesbian, gay, bisexual, and transgender (LGBT) population. An anonymous pre- and post-test questionnaire was developed to assess the providers' knowledge and attitudes about common health conditions in LGBT adolescents (Wahlen et al., 2020). The study found a substantial increase in provider knowledge, which could help improve health outcomes of adolescents in the

LGBT population (Wahlen et al., 2020). In a study by Moon & Hyun (2019), a randomized control trial was done to assess the effectiveness of a blended learning method by incorporating cardiopulmonary resuscitation (CPR) videos and a face-to-face lecture in providing CPR education to nursing students. The participants of the study completed a pre- and post-test questionnaire to evaluate knowledge, attitude, and self-efficacy on CPR education (Moon & Hyun, 2019). The results of the study showed an improvement in the nursing students' knowledge and attitudes regarding CPR when using a blended learning method (Moon & Hyun, 2019). Another study by Harden et al. (2017) aimed to improve the knowledge, attitudes, and behaviors of oncology nurses regarding palliative care by developing an educational program that focused on palliative care. The study also utilized a pre- and post-test questionnaire, which results indicated an increase in the oncology nurses' knowledge, attitudes, and behaviors regarding palliative care (Harden et al., 2017). There are pre- and post-test guidelines developed by the Brigham and Women's Hospital Center for Nursing Excellence to assess the impact of educational programs (Brigham and Women's Hospital, 2023).

### **Stakeholder Identification**

The department heads of the pediatric and family medicine clinics at the MTF supported the educational intervention to increase health care provider knowledge and confidence of DS management, which made them valuable stakeholders in this evidence-based practice project. Additionally, a clinical mentor and pediatric primary care provider at the MTF, who served as a representative of the MHS Southern California DS Care Group, was also an important stakeholder for the project. Effective communication and regular follow-ups with the stakeholders helped facilitate a seamless implementation for the educational intervention.

### **Implementation Barriers**

A potential barrier identified for this project was the lack of communication within the MTF regarding the AAP's published health supervision guidelines for DS and other available DS-specific resources within the MHS. This may be attributed to providers having little to no experience caring for pediatric patients with DS as well as a high turnover of military staff. Another potential barrier identified was the lack of a validated screening tool to determine the efficacy of the educational intervention to providers, which resulted in the development of a pre- and post-test survey for the evidence-based practice project. Additionally, since the participants completed the post-test surveys immediately after the educational intervention, there was no follow-up to determine if the PCPs were utilizing the updated 2022 AAP Down Syndrome health supervision guidelines, as well as the DHA Pediatrics app, and CarePoint Military Portal within their clinical practice.

### **Project Approval**

The MTF's Institutional Review Board (IRB) approved the evidence-based practice project on October 25, 2022. Approval from the University of San Diego (USD) IRB was received on November 4, 2022.

This project focuses on educating health care providers about guidelines for providing primary care to children and adolescents with DS. There was no potential harm identified in this educational intervention. The participants who completed the surveys were kept anonymous.

### **Project Methods and Implementation**

After obtaining IRB approval from the MTF and University of San Diego, an educational PowerPoint presentation was developed, focusing on DS management for the pediatric population and the updated 2022 AAP Down Syndrome health supervision guidelines. The

project also consisted of the development of a pre- and post-test survey for DS-specific care to assess a measure of the providers' knowledge and confidence on DS management. The surveys were based on a 5-point Likert scale, which consisted of a total of 5 questions, as outlined in Table 1. The 5-point Likert scale asked the survey participants to rank their responses of each statement on a rating scale from strongly disagree, disagree, neither agree nor disagree, agree, and strongly agree. The anonymous surveys were administered to the providers as a hardcopy at the beginning of the educational training sessions. Immediately after the PowerPoint presentation on DS management, the providers were asked to complete the post-test survey located on the back side of the pre-test. The participants were asked to complete the survey to help measure the value of the educational training session and for quality improvement purposes.

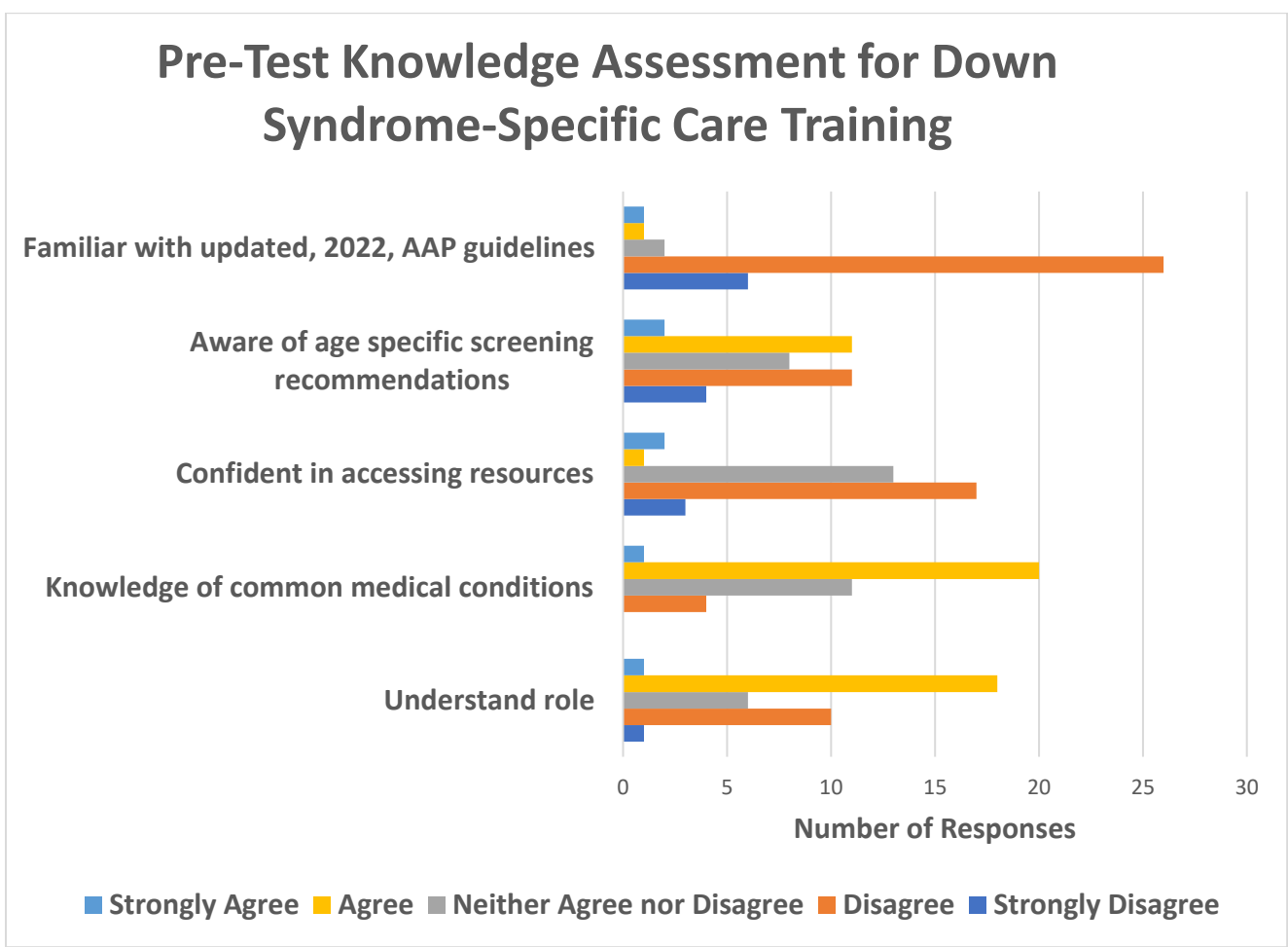
The educational training sessions were held in person at the MTF on two separate occasions, one to pediatric primary care providers and the other to family medicine primary care providers. The educational intervention on DS management was delivered as a PowerPoint presentation, which included a brief overview of DS, discussed some of the most common medical conditions associated with the disorder, the impact of the MHS on military children and families with special health care needs, available resources on DS-specific care within the MHS, and the updated 2022 AAP Down Syndrome health supervision guidelines in taking care of pediatric patients with DS. The duration of the project implementation was approximately 30 minutes, which was the allotted time given for the educational training session.

**Table 1***Pre- and Post-Test Questions Included in the Survey*

	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Neither Agree nor Disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
I understand my role in providing Down syndrome-specific care	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
I am knowledgeable about the most common medical conditions associated with Down syndrome	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
I am confident in accessing available resources for Down syndrome-specific care within the military health system	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
I am aware that there are age-specific screening recommendations when caring for children with Down syndrome	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
I am familiar with the 2022 American Academy of Pediatrics (AAP) – “Health Supervision for Children and Adolescents with Down Syndrome”	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

**Figure 1**

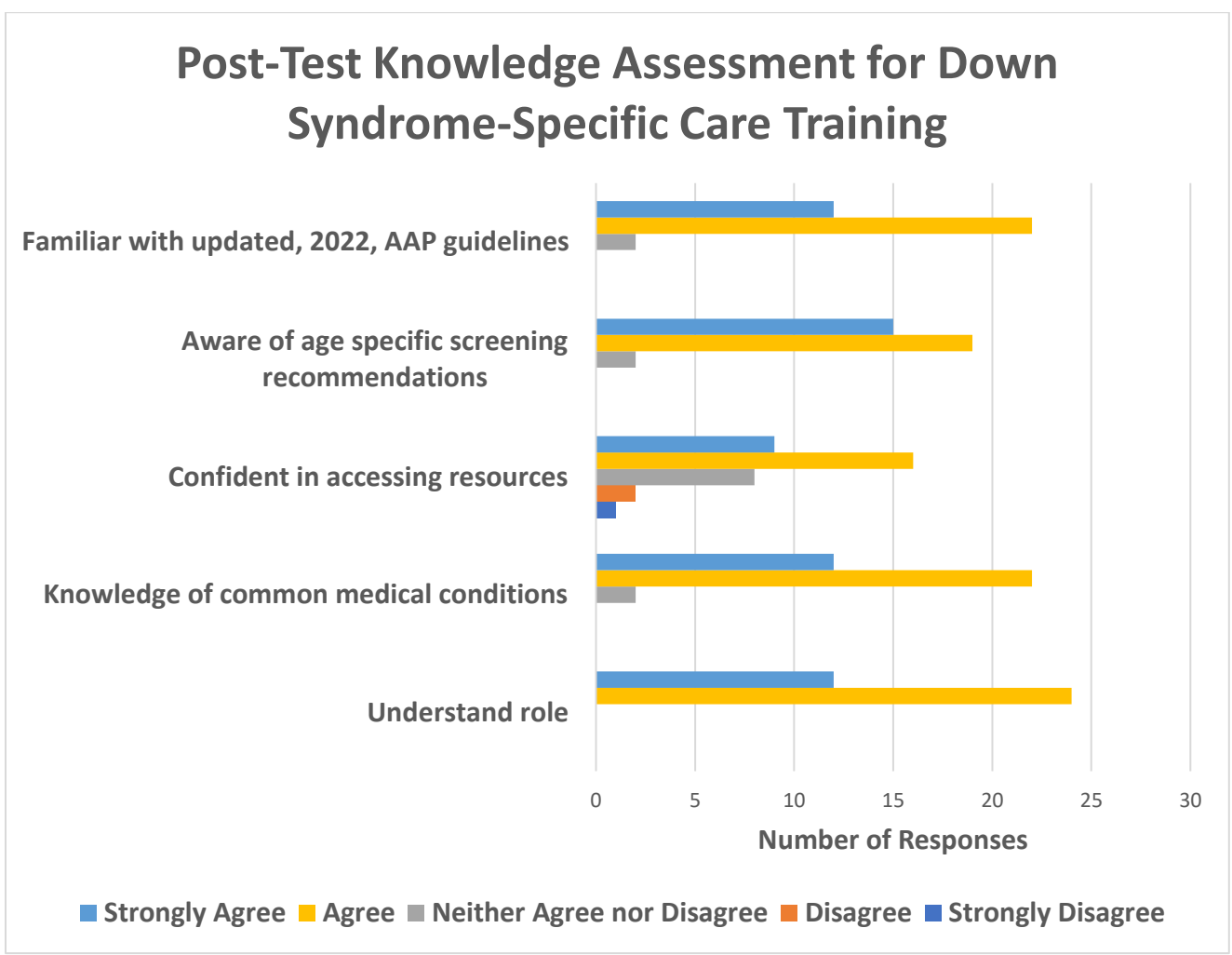
*Average Scores Pre Education*





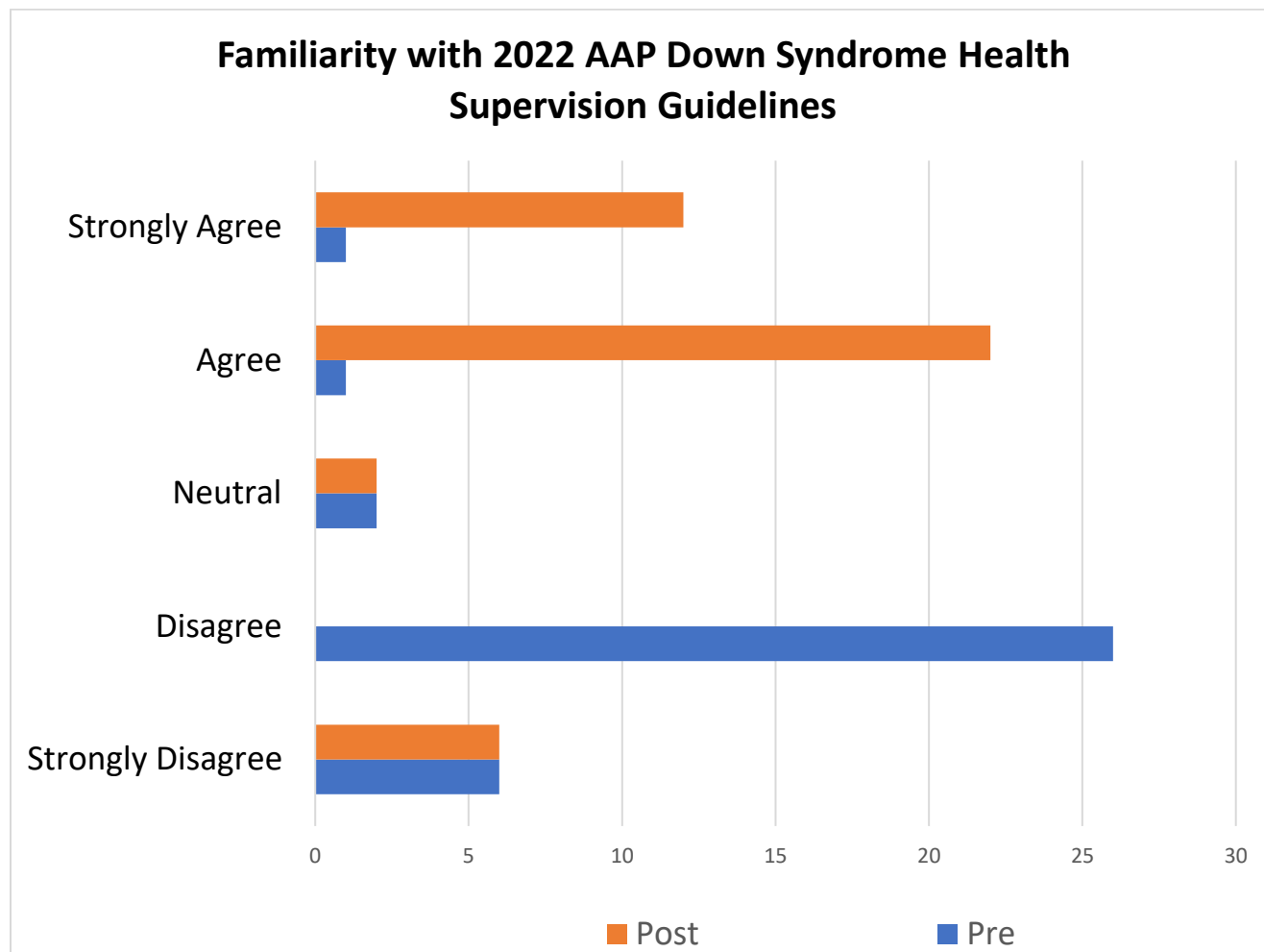
**Figure 2**

*Average Scores Post Education*



**Figure 3**

*Pre and Post Education for Provider Familiarity of AAP Down Syndrome Health Supervision Guidelines*



### **Implications for Clinical Practice**

Utilization of the 2022 AAP Down Syndrome Health Supervision Guidelines can improve care for children and adolescents with DS. Additionally, pediatric resources such as the DHA Pediatrics App and the Carepoint Military Portal can also be used in other MTFs to enhance delivery of care and help PCPs gain a better understanding of the important screening guidelines for DS management.

### **Cost Benefit Analysis**

After factoring in the total costs of professional time such as development of the educational program, provider time spent to attend the training session, along with the cost of supplies such as printing and duplication of handouts, the total came out to \$4,728.00. However, based on the literature, the average health care costs for an individual with DS for the first 18 years of life is nearly \$230,000 to insurers (Kageleiry et al., 2016). The financial benefits were difficult to quantify due to the lifelong care that is required for an individual with DS. For non-financial benefits, this educational intervention can improve care for children and adolescents with DS, and early identification of coexisting medical conditions could help reduce any further complications.

### **Project Dissemination**

A poster presentation with summary was presented to the University of San Diego, Hahn School of Nursing students and faculty at the DNP Presentation Day, which was held on March 13, 2023. The evidence-based project was then disseminated at the MTF's Annual Continuous Process Improvement Symposium on March 14, 2023. A stakeholder presentation was conducted on April 5, 2023 via zoom to the clinical mentor and clinical faculty.

### **Conclusions**

Children with DS are at an increased risk for developing serious health conditions, especially in the earlier years of life. PCPs are in a valuable position to identify these health issues early, to provide the best care, treatment recommendations, and referrals to appropriate services. Provider education on the current DS guidelines and the provision of military DS-specific resources can improve patient outcomes and quality of life. This educational

intervention is an effective way to help PCPs deliver optimal care for children and adolescents with DS.

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