

**Improving Healthcare for Spanish-Speaking Special Olympics Athletes
in Chatham County, North Carolina**

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Abstract

Special Olympics is the world's largest sports organization for people with intellectual and developmental disabilities (IDD). Special Olympics Health was created in 1997 to focus more on the health of the athletes, who suffer from many healthy disparities. This led to the development of MedFest, an event to offer free health screenings and sports physical exams for all Special Olympics athletes. Special Olympics North Carolina identified a need in Chatham County, NC to increase access of their sports programs and health programs to athletes and families who are Spanish-speaking. The goal of this project was to improve provider comfort and communication with IDD patients both for providers at MedFest events and more importantly for providers in the community. Secondly, this project aimed to improve the referral process by which these patients find consistent and appropriate care. A training video was implemented which included information about common medical issues, common barriers to healthcare, various communication techniques, and additional resources for providers to use for IDD care. After modifications utilizing the Plan, Do, Study, Act methodology, the video was found to increase provider comfort and understanding of IDD care. A Referral Tool to facilitate ease of referral from MedFest to primary care or specialty care providers as needed was created as a template for future use given low participation by Chatham County providers.

Keywords: Intellectual and developmental disabilities, IDD, Special Olympics, MedFest

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Section I. Introduction

Background

Special Olympics is the world's largest sports organization for people with physical and intellectual disabilities (Special Olympics Health, 2020). The mission of Special Olympics is to provide year-round athletic competitions in a variety of sports for all people with intellectual disabilities to improve physical fitness, overall health, and inclusion (Special Olympics, 2020). In 1997, Special Olympics Health was created to improve the health of Special Olympics athletes (henceforth referred to as “athletes”), a community that is often underserved in regards to medical care (Special Olympics Health, 2020). This inclusive health initiative led to MedFest, an event to offer free health screenings and sports physical exams for athletes of all ages (Special Olympics North Carolina, 2020).

Special Olympics as an organization has identified the need for increased resources for the Hispanic community. As a whole, the Hispanic community suffers from several health care disparities, such as higher rates of obesity, diabetes, and liver disease, as well as lower life expectancy as compared to non-Hispanic Whites (Office of Minority Health, 2018). Major influencing factors for these disparities include lower rates of higher education, median income, and health insurance coverage (Office of Minority Health, 2018). Members of the Hispanic community suffering from an intellectual or developmental disability (IDD) therefore face greater challenges in regards to their health, thus creating a need for this DNP project.

Organizational Needs Statement

The Special Olympics of North Carolina (SONC) has identified a need in Chatham County, North Carolina to increase access of their sports programs and health programs to athletes who are Spanish-speaking or who have Spanish-speaking parents. According to Ellen

Fahey, Health Director for SONC, this issue of reaching the Hispanic community was recently brought to light. A parent of a Chatham County Special Olympics athlete is a Hispanic registered nurse and very involved in MedFest coordination. She verbalized that some parents of Special Olympics athletes do not speak English and thus miss out on the health benefits that MedFest and Special Olympics Health have to offer (E. Fahey, personal communication, April 8, 2020).

Chatham County is primarily rural with limited health resources. The Hispanic community has grown over the past several years in Chatham County. The percent of foreign-born residents has increased from 8.48% percent in 2016 to 8.63% percent in 2017, indicating a potentially greater population of residents who do not speak English proficiently (Data USA, 2017). The language barrier between provider and patient makes healthcare especially challenging for those patients who belong to this community and the special needs community. SONC would like to assess the current resources of Chatham County by determining which providers are educated in working with both Spanish-speaking and IDD patients, then work to increase these resources.

This need aligns with the Healthy People 2020 leading health initiatives of Access to Healthcare Services and Nutrition, Physical Activity, and Obesity (ODPHP, 2020). By broadening the reach of MedFest to as many athletes as possible, people with IDD can participate in the sports programs of Special Olympics to improve physical fitness and reduce obesity. People with IDD are more likely to be obese than people without IDD, so regular physical activity is critical (Special Olympics Health, 2020). In addition, it addresses the Healthy North Carolina 2030 initiative of Access to Exercise Opportunities (NC Department of Health and Human Services, 2020). This particular organizational need relates directly to improving access to exercise opportunities for special needs people in the Hispanic population.

The Institute for Healthcare Improvement (IHI) developed a framework called the Triple Aim to define three dimensions that must be improved to optimize healthcare. These three dimensions are: improving the health of a population, enhancing the experience of the individual, and reducing the per capita cost of healthcare (IHI, 2020b). The newly identified need of the Special Olympics to expand its healthcare reach to the Hispanic community aligns with these three dimensions. MedFest enhances the experience of care for individuals with disabilities, a vulnerable population with significant health disparities, by providing fun, inclusive, and meaningful experiences for athletes. By identifying necessary resources to communicate effectively and efficiently with the Spanish-speaking population at these events, the healthcare resources available at these events will reach a greater number of patients. This, therefore, improves population health both within the Spanish-speaking population and overall. The per capita cost of healthcare will be reduced because MedFest programs have been shown to discover other life-threatening conditions that may have otherwise gone unnoticed if no care was provided. Regular medical screenings, education about healthy lifestyles, and appropriate referrals can reduce chronic diseases and, thus, reduce overall cost.

Problem Statement

The strong resources for health screenings and referrals for people with IDD provided through MedFest are not adequately reaching the growing Spanish-speaking population in Chatham County, NC. There is a need to improve provider comfort and communication with IDD patients both at MedFest and in the community and to improve the referral process by which these patients find consistent and appropriate care.

Purpose Statement

The purpose of this DNP project was to assess the availability of providers in Chatham County that can appropriately care for people with IDD who are primarily Spanish-speaking or whose parents are primarily Spanish-speaking. After conducting this county assessment, the project worked to improve resources through training healthcare workers in the area to increase comfort with caring for IDD patients. To ensure that the Spanish-speaking community is adequately cared for, a tool to improve referral from MedFest to primary care or specialty care was developed. The goal is for the tool to include availability of Spanish interpreters, location of practice, and various insurance acceptance to best serve the diverse needs of this community. Increased access to care and improved inclusion in SONC-sponsored activities has the potential to improve overall health for those living with disabilities.

Section II. Evidence

Literature Review

Improving Access with Communication

The literature review took place in three phases. The problem ultimately relates to a communication issue between the Special Olympics and the athletes that are Spanish-speaking or who have Spanish-speaking parents. Without adequate communication, these athletes may miss out on MedFest events, important medical referrals critical to their health, and the physical activity that Special Olympics provides for these individuals. The first phase included a search for improving communication for people with intellectual and developmental disabilities (IDD). The second phase included a search for improving communication with Spanish speaking patients. Finally, a third phase combined the two populations and was a search for communication with patients with IDD in the Hispanic community.

For the first phase, a search through PubMed was performed utilizing the phrase "Improving care for intellectual and developmental disabilities". After limiting the search to articles published within the past five years and in the English language, this search rendered 20 results. The titles and abstracts were then reviewed, and relevant articles were read in their entirety. The total yield for this search was four articles. There was one article with evidence level II, two articles level IV, and one level VI. It was important to keep the level VI article even if it had a lower level of evidence because the qualitative information will help to formulate the intervention of this project.

The second phase, researching communication with Spanish-speaking patients, was also conducted through PubMed. The search phrase [(Communication) AND Spanish-speaking parents) AND methods] was used. MESH terms included "communication", "parents", and

"methods". The term "parents" was selected because Ellen Fahey communicated that she would like the target population to include children with Spanish-speaking parents, since this seems to be the greatest gap in care with relation to access to MedFest (E. Fahey, personal communication, April 8, 2020). This search yielded 44 articles. The limitations included within 5 years of publication and the English language. Abstracts were analyzed and three articles were selected to be read in their entirety. There was one article evidence level III and two articles evidence level IV.

The final phase combined Spanish-speaking and IDD to target literature for the very specific population of this project. A PubMed search was performed utilizing the phrase [(Hispanic) OR Latino) AND intellectual disability) AND health care]. MESH terms included "Hispanic American", "intellectual disability", and "delivery of health care". The search was only limited to the English language due to the specific nature of the search. Thirty-nine articles resulted from this search and, after reviewing abstracts, two were selected as appropriate to be read in their entirety. One article was published in 2014, outside of the 5-year requirement, but provided important and relevant information and was evidence level III. The other article selected was evidence level VI, but provided important qualitative information.

Current state of knowledge

There is limited literature on the current state of knowledge for adequate communication with patients who belong to both the IDD population and the Spanish-speaking population. However, there is the knowledge that these individuals have a compounded disparity because they belong to two minority groups (Scott & Havercamp, 2014). This disparity is a complex issue with many moving parts. Variables such as income level, insurance access, language barriers, discrimination, and living situation all contribute to the decreased likelihood that a

patient is receiving routine healthcare services and screenings (Scott & Havercamp, 2014). Any individual of a racial or ethnic minority is less likely to have these regular screenings. Still, Hispanics with IDD are significantly less likely to receive some normal screenings as compared to other minorities with IDD (Scott & Havercamp, 2014).

There is also knowledge that proper screenings and primary care for individuals with IDD are very impactful. A randomized study performed in Canada found that more primary care visits led to fewer emergency department (ED) visits for people both with and without IDD (Durbin et al., 2018). However, the difference was even more significant for IDD patients. There was a 12.1% decrease in ED visits for IDD patients who had greater than three primary care visits while only a 5.2% decrease was noted for those without IDD (Durbin et al., 2018). This study emphasized the importance of continuity of care for these patients, developing a strong provider-patient relationship, allowing for extended patient visits to facilitate communication, and assisting them through a complex healthcare system for optimal results (Durbin et al., 2018).

A small qualitative study by Selick et al. (2018) noted the barriers to successful care of IDD patients, which must also be taken into consideration during the development of this project. This study interviewed staff to evaluate an intervention to improve the care of IDD patients in both primary care and ED settings. The most significant barrier noted by the staff was that these general settings see a wide range of patients, with only about 1% of the population being classified as IDD (Selick et al., 2018). Due to the low percentage of patients with an IDD classification, the staff faced significant challenges in implementing practice changes to address the unique needs of this patient type (Selick et al., 2018).

For communication with Spanish-speaking patients, there is a National Standard of Practice for the use of professional interpreters in healthcare. These standards were developed to

improve the training and consistency of the services provided by professional interpreters. A professional interpreter will provide accurate translation without omissions or substitutions and maintain confidentiality, impartiality, and cultural sensitivity (National Council on Interpreting in Health Care, 2005). Professional interpreter use has been associated with better outcomes for patients with limited English proficiency (LEP). However, this service is still under-utilized in this country, often relying on broken conversations or family interpretation (Gutman et al., 2018). Even providers that utilize a professional interpreter often leave out critical information that may have otherwise been communicated with a typical English transaction (Gutman et al., 2018). Following national standards of practice, greater exposure to professional interpreters is imperative for better health outcomes for those with limited English proficiency.

Current approaches to solving population problem(s)

While the current approaches to providing more Spanish-speaking IDD patients appropriate health care and screenings are limited, there is information on how to approach these groups independently. In a retrospective study by Durbin et al. (2019), a health checklist was found to be useful in providing more comprehensive preventative care for those with IDD and also increased the staff's comfort for caring for these individuals. In addition, Special Olympics currently uses an online platform of modules for providers to watch before MedFest events. These are designed to help these providers feel more comfortable with caring for and communicating with this population and to be made aware of some abnormalities that may be more common in this group (Special Olympics, 2017). In an article by Seidenberg & Eggers (2015), an overview of the purpose of MedFest is provided as well as critical parts of the physical exam that should be performed to provide these athletes with the best possible care. All

three of these interventions have been successful resources for providing appropriate healthcare for people with IDD.

A study by Singelis et al. (2018) evaluating health communication utilizing culturally sensitive Spanish materials found that both surface structure and deep structure have positive effects on communication. Deep structure refers to the written material that maintains appropriate cultural beliefs, values, tone of writing, and formality for that culture. Surface structure refers to images that people of that culture can relate to. After controlling for both factors, it was found that both deep and surface structures of a pamphlet increased the knowledge of the reader (Singelis et al., 2018).

Another important approach was concluded in a qualitative study by Gibbons et al. (2016) that evaluated the perception of healthcare and the wellbeing of people with IDD who were using Medicaid managed care. One of the greatest challenges the survey participants endorsed was the confusion about care coordination. Many were unsure if they had a care coordinator to help them navigate referrals, appointments, and complex medical issues or they were unsure what a care coordinator was responsible for (Gibbons et al., 2016). While care coordination is something provided by Medicaid and much of the target population will be Medicaid recipients, this project intervention must simplify the navigation of the healthcare system as much as possible.

Evidence to support the intervention

The intervention for this project planned to include an assessment of providers in Chatham County, development of training for providers, and coordination of a list of providers to utilize at future Chatham County MedFest events. Ellen Fahey communicated that Special Olympics North Carolina does not have knowledge of which providers in Chatham County can

be utilized to care for the Spanish-speaking patients with IDD (E. Fahey, personal communication, April 8, 2020). Therefore, the first objective of this intervention was to evaluate the baseline resources of Chatham County. Providers in Chatham County were asked about comfort with IDD patients, availability of a Spanish interpreter, what insurance plans they accept, and willingness to be a referral partner for Special Olympics MedFest events.

The second part of this intervention was to create a training program for providers to increase their comfort with caring for IDD patients, especially those in the Hispanic community. After understanding common barriers to sustainability that were mentioned previously, these providers were provided a health checklist and resources to simplify the care of patients with IDD and to ensure that this intervention is sustainable. The goal of this phase was to expand the resources that were discovered in the first phase.

Finally, there was a plan to create a list of providers specifically for Chatham County. The information on this list was to include provider name, location, contact information, age group of care, specialty, insurance acceptance, and interpreter availability. This list will allow for ease of care coordination by the MedFest team, helping to address a problem that is often associated with patients in the IDD population (Gibbons et al., 2016). The providers during MedFest events will use this list as a way to refer athletes requiring further care to other providers in the area who have undergone training for IDD and can also provide culturally specific care with language interpretation if needed.

Evidence-Based Practice Framework

Identification of the framework

For the proposed DNP project, the Plan-Do-Study-Act (PDSA) improvement framework was utilized to construct, evaluate, improve, and maintain the intervention. PDSA is a system developed by the Institute for Healthcare Improvement that focuses on setting a specific aim with defined measures (IHI, 2020a). The aim should work to improve one of the following six aspects of healthcare: safety, effectiveness, patient-centeredness, timeliness, efficiency, or equitability (IHI, 2020a). A plan is developed to create change for improvement (Plan), the intervention is executed (Do), the results of the measures are studied for effectiveness (Study), and finally, the results are used to modify the intervention for better results (Act). The PDSA cycle can be performed multiple times to optimize an intervention (IHI, 2020a).

This DNP project aimed to increase health care providers' comfort level with caring for IDD patients and develop a referral tool as a way to focus on the Spanish-speaking population. This planned aim will improve the equitability of care for Spanish-speaking IDD patients (and all IDD patients in Chatham County), the efficiency of the referral process from MedFest to other providers, and safety for the specific needs of IDD patients. The intervention plan included a training video to educate providers about various aspects of IDD care. Providers completed a survey before and after the training module to assess for improvement in comfort level. The results of the survey were evaluated for ways to improve the training process and changes were made as needed. Each PDSA cycle for this project took approximately one month to complete and, therefore, there was a total of three cycles.

Ethical Consideration & Protection of Human Subjects

The project was designed to improve comfort with IDD patients in Chatham County so that MedFest and other healthcare options become more easily accessible for Hispanic patients with IDD. Since this is a process improvement specific to Chatham County, it did not involve generalizable research or human subjects (Hicks, 2018). The same intervention, however, may be used in other North Carolina counties if successful. The intervention was equal for all in the target population because the final list of providers will be used for all athletes at the MedFest events with the specific intention of broadening access of care to Hispanic athletes. No risk of ethical harm or neglect was discovered when evaluating this project. Formal ethical training was completed by the DNP student through the CITI Program online in which the Social/Behavioral Research Investigators and Key Personnel course was completed. No formal institutional review board (IRB) or other approval process is required through Special Olympics. The need for an IRB was also evaluated through East Carolina University and the review demonstrated no need for an IRB.

Section III. Project Design

Project Site and Population

Description of the Setting

The setting for this project was Chatham County and Special Olympics of Chatham County. An evaluation was completed for current healthcare resources and the intervention intended to expand these resources for the athletes who attend MedFest, with special attention to the Spanish-speaking population.

Chatham County is located in central North Carolina west of the state capitol, Raleigh. It is comprised of 682 square miles, 97.5% of which are rural areas (Godbout et al., 2018). There are four towns within Chatham County: Pittsboro, Siler City, Goldston, and Cary. The ethnic makeup of Chatham County is 82.2% White, 12.7% Black, 12.5% Hispanic, 2% Asian, 1.2% American Indian or Alaskan Native, and 1.8% multiracial. Over 43% of Siler City residents identify as Hispanic and greater than 11% of all Chatham County residents speak Spanish in the home (Godbout et al., 2018). North Carolina as a whole is comprised of 70.6% White, 22.2% Black, and 9.6% Hispanic, demonstrating some significant demographic differences in this particular county (United States Census Bureau, 2019). The larger Spanish-speaking presence in Chatham County raises certain healthcare questions about interpreter availability and access for the uninsured or underinsured, thus creating a need for this DNP project.

Description of the Population

The population that was evaluated is healthcare providers in Chatham County. The goal was for all healthcare providers to be contacted to create a large resource tool for appropriate referral partners to meet the specific needs of each MedFest athlete. These providers include

primary care, pediatrics, cardiology, gynecology, urology, gastroenterology, ear/nose/throat, ophthalmology, mental health, dentists, and orthopedics.

The population that benefits from this intervention is the athletes at Chatham County MedFest events. This includes individuals ages 8 and older (with no upper age limit) with a wide spectrum of intellectual and developmental delays. These may include Downs Syndrome, Williams Syndrome, Autism, Muscular Dystrophy, or Fragile X Syndrome, among many others. Each of these disorders comes with specific health risks, many of which may need to be further evaluated after a sports screening by the providers at MedFest. By developing this resource, the referral process will be streamlined and simplified.

In addition, this intervention has a special focus on communication with athletes and families who are Spanish-speaking by addressing the added identified barriers to proper care for those individuals, which may include language barriers, travel barriers, cost barriers, and insurance barriers. This tool gives Medfest providers a streamlined method of referring athletes to a healthcare provider for follow up that overcomes these common barriers. This will make obtaining appropriate healthcare as easy as possible for the families of athletes.

Project Team

The site champion for this project team was Ellen Fahey, Health Director for Special Olympics North Carolina. She served to approve the implementation tool and provide the Special Olympics training modules that were used for the intervention. After completion of the project in Chatham County, Ms. Fahey will work to spread this intervention to other counties to improve MedFest events throughout North Carolina.

The DNP student leading this project collected the names and information of providers, implemented the training, and surveyed the providers before and after training, and formulated

the referral tool. The student was responsible for collecting and analyzing all data retrieved from the surveys to make conclusions and recommendations about the use of this intervention in Chatham County and the possibility of other counties in North Carolina.

Project Goals and Outcome Measures

The outcome measure that this project intended to achieve is improved access to care for Hispanic Special Olympics athletes by improving the process in which athletes find primary and specialty care providers. Due to time constraints and the fact that all MedFest events were cancelled due to COVID-19 during the implementation of this project, process measures were evaluated for future Medfest events. The goal of the intervention was to improve provider comfort with IDD care in the community as well as the referral process from MedFest to either primary care or specialty care providers based on the athlete's needs. By improving this process, it will help all athletes get regular and adequate medical care outside of MedFest events. The referral list will also indicate which providers have interpreter availability to make it culturally sensitive for Spanish-speaking athletes or athletes with Spanish-speaking parents.

Description of the Methods and Measurement

The proposed method of improving health providers' comfort with IDD patients was a training video created by Special Olympics and approved by Ellen Fahey. The training addresses communication techniques, common medical issues, and common barriers to healthcare that will be useful to healthcare providers. Participants completed a pre-survey prior to the training and a post-survey after the training. The pre-survey was composed of nine questions that ask about the provider's comfort level with various aspects of patient care, including formulating a plan of care, communication, informed consent, behavioral crises, and finding appropriate resources. The first five questions have the same five available responses that follow a Likert Scale design:

very uncomfortable, somewhat uncomfortable, neither comfortable nor uncomfortable, somewhat comfortable, and very comfortable. Each of these answers was designated a score from one to five with one being "very uncomfortable" and five being "very comfortable". The final four questions were content questions that directly relate to the training module. Each correct answer earned one point. The post-survey was identical to the pre-survey except for the addition of one question that asks about the number of patients diagnosed with IDD that the provider has cared for in the past year and two free-text questions where providers could elaborate on how the training was helpful and suggestions to improve the training process. The pre-survey and post-survey scores were totaled and the difference between post-survey and pre-survey were utilized to assess the perceived benefit of the training. Using these numbers and the suggestions from the free-text answers, training was modified as needed to meet the needs of providers following the PDSA improvement cycle.

Discussion of the Data Collection Process

Data was collected through an online survey created via Google Forms. The providers were sent an email that included links to the pre-survey (see Appendix A), training module, and post-survey (see Appendix B). Detailed instructions were included in the email so that the participants understood to complete the process in that order. The DNP student's contact information was provided in case of any technical difficulties with the process. The data received was only accessible by the DNP student on a password-protected Google portal and will have no identifying data of the providers.

Implementation Plan

A training module created by Special Olympics was the implementation tool to improve providers' comfort with caring for IDD patients. By increasing the comfort of all providers in

Chatham County and then classifying those providers in the referral tool in regards to specialty, interpreter availability, location, and insurance acceptance, healthcare barriers for this population can be minimized.

Timeline

The implementation took place over five months. Final preparations took place in July 2020 during which the training module was approved by Ellen Fahey and the list of providers to be evaluated and trained was completed. In August 2020, the first third of providers completed the pre-survey, training module, and post-survey. Feedback from the post-survey and analysis of the change in scores between pre-survey and post-survey will be used to adjust the training module as necessary utilizing the PDSA improvement cycle. This modified training module was administered to the second third of providers in September 2020. The feedback and results from the surveys was again utilized to adjust training as necessary. The new training was administered to the final third of providers in October 2020. In November 2020, all results were consolidated to evaluate the data and the changes that were made with each PDSA cycle. After analysis and review with Ellen Fahey, the intervention was evaluated for use in other North Carolina counties and MedFest events.

Section IV. Results and Findings

Results

Data Collection Process

The data that was collected from this project included both qualitative and quantitative information that was gathered from the survey given to providers before and after the training video. The first five questions of both the pre-survey and post-survey addressed the providers' comfort level with various aspects of IDD care and the questions were identical on both surveys (see Appendix A, Appendix B). These questions followed a five-point Likert-scale design and ranged from "very uncomfortable" to "very comfortable". Each of these answers was then assigned points ranging from 1 to 5 with 1 being "very uncomfortable" and 5 being "very comfortable". The average score of the providers in each round was calculated by multiplying the number of points for each answer with the percentage of providers who answered in that fashion (Table 1). A round is defined as an implementation including the pre-survey, training video, and post survey given to a group of providers. There were three rounds total in this project. The improvement between the pre-survey and post-survey for each round was then recorded, which was calculated by subtracting the pre-survey average score from the post-survey average score (Table 1).

The following four questions were "content questions" that directly assessed understanding and retention of information from the training video. These were presented in either multiple choice or true/false format. The percent of correct answers on the pre-survey versus the percent of correct answers on the post-survey was compared for each of these four questions. A percent improvement was then calculated by subtracting the pre-survey value from the post-survey value (Table 2). All four questions were identical on both surveys (see Appendix A, Appendix B).

The post-survey had three additional questions to provide qualitative answers. The questions asked the providers to evaluate the training video and give suggestions for improving the training via free-text answers. Answers were used to help facilitate project improvement in conjunction with the quantitative information gathered from the first nine questions. The final question on the post-survey inquired about how many IDD patients the provider had cared for in the past year, which was information specifically requested by Special Olympics North Carolina.

As noted previously, three rounds of implementation were performed with improvements made to the training video implementation between each round. A different group of providers was used for each round. Round one was composed of four providers: two medical doctors (MD), one nurse practitioner (NP), and one health services provider psychologist (HSP-P). Round two was composed of nine providers: three MDs, two NPs, one HSP-P, one registered dietitian (RD), one physician assistant (PA), and one doctor of osteopathic medicine (DO). Round three was composed of eight providers: two MDs, four NPs, one PA, and one registered nurse (RN). Each round of implementation was conducted over about one month, allowing for adequate time for the providers to complete the training and provide feedback via the surveys.

Data from “Comfort Level” Questions

Round one of implementation. Only one of the four providers that were sent the surveys and training in this round completed the pre-survey. No providers completed the post-survey. An email from the provider that completed the pre-survey and part of the training video stated “The interface is HORRIBLE. Presentation is slow with no speed adjustment that I could find, and the design required me to “babysit” the player and constantly click different buttons and such on the screen to play videos and other detailed info. As such, it was taking more time than I could allow at this time.” (H.B. Scheffler, personal communication, August 28, 2020). This feedback was

used to modify training to a short 11-minute video with the same information from the original training that could be played via YouTube. Since no post-surveys were completed, no data to assess improvement after training was obtained during this round (Table 1).

Round two of implementation. Three of the nine providers in this round completed the pre-survey, training, and post-survey. Question one had a 2.0-point increase in comfort level, question two had a 1.5-point increase, question three had a 0.75-point increase, question four had a 0.67-point increase, and question five had a 2.33-point increase. While comfort level increased on all measures, the participants remained most uncomfortable with informed consent and management of behavioral crises as noted by questions three and four. The training was modified to include more information on these two topics.

Round three of implementation. All eight providers in this round completed the pre-survey, training, and post-survey. Comfort level increased on all measures. Question one had a 0.75-point increase in comfort level, question two had a 1.77-point increase, question three had a 1.22-point increase, question four had a 1.28-point increase, and question five had a 1.27-point increase. There was an improvement in the increase in comfort for informed consent and management of behavioral crises, as was the intention of the modifications for this round. Question one had the least amount of improvement, but the pre-survey score was also higher in this round.

Data from “Content” Questions

Round one of implementation. The one provider that completed the pre-survey answered each question correctly. However, since this provider did not complete the post-survey, no percent improvement was able to be calculated (Table 2).

Round two of implementation. There was a 25% improvement noted for question six, 0% improvement for question seven, 0% improvement for question eight, and -8.3% improvement for question nine. Even though questions seven and eight had no improvement, all providers answered the questions correctly before and after the training (Table 2). The decrease in content retention for question nine was most concerning, so information related to communication was evaluated. Ultimately, no information was changed, but the order of some slides was modified (per site champion) to facilitate flow and information retention.

Round three of implementation. An 11.10% increase was noted for question six, 22.2% increase for question seven, 0% increase for question eight, and 9.7% increase for question nine. Again, question eight demonstrated no improvement because all providers answered this question correctly on both the pre-survey and post-survey (Table 2).

Table 1
Average Provider Scores and Improvement Results of Comfort Level Questions

	Round 1			Round 2			Round 3		
	<i>Pre-Survey Average Score</i>	<i>Post-Survey Average Score</i>	<i>Improvement</i>	<i>Pre-Survey Average Score</i>	<i>Post-Survey Average Score</i>	<i>Improvement</i>	<i>Pre-Survey Average Score</i>	<i>Post-Survey Average Score</i>	<i>Improvement</i>
Question 1: How comfortable are you formulating a plan of care for someone with IDD?	5	n/a	n/a	3	5	2	3.55	4.25	0.75
Question 2: How comfortable are you with appropriate ways to communicate with IDD patients?	5	n/a	n/a	3.5	5	1.5	2.98	4.75	1.77
Question 3: How comfortable are you with informed consent for IDD patients?	3	n/a	n/a	3.25	4	0.75	2.78	4	1.22
Question 4: How comfortable are you handling a behavioral crisis for an IDD patient?	4	n/a	n/a	3	3.67	0.67	2.22	3.5	1.28
Question 5: How comfortable are you finding appropriate resources for care of IDD patients?	2	n/a	n/a	2	4.33	2.33	3.11	4.38	1.27

Note. Average score based on percentage of providers for each answer option. 1 point = “very uncomfortable”, 2 points = “somewhat uncomfortable”, 3 points = “neither comfortable nor uncomfortable”, 4 points = “somewhat comfortable”, 5 points = “very comfortable”.

Improvement is post-survey average score minus pre-survey average score.

Table 2
Content Question Analysis and Percent Improvement

	Round 1			Round 2			Round 3		
	<i>Pre-Survey Percent Correct</i>	<i>Post-Survey Percent Correct</i>	<i>Percent Improvement</i>	<i>Pre-Survey Percent Correct</i>	<i>Post-Survey Percent Correct</i>	<i>Percent Improvement</i>	<i>Pre-Survey Percent Correct</i>	<i>Post-Survey Percent Correct</i>	<i>Percent Improvement</i>
Question 6: All of the following are barriers to health for people with IDD EXCEPT:	100%	n/a	n/a	75%	100%	25%	88.90%	100%	11.10%
Question 7: True or False: Neurodevelopmental disorders may result in intellectual disability, seizure disorder, psychiatric disturbances, communication difficulties, and sensory deficits. These neurodevelopmental disorders are caused strictly by genetic defects.	100%	n/a	n/a	100%	100%	0%	77.80%	100%	22.20%
Question 8: In addition to the neurological system, a neurodevelopmental disorder may affect the development of which other system(s)?	100%	n/a	n/a	100%	100%	0%	100%	100%	0%
Question 9: The best way to communicate with a patient with IDD is to:	100%	n/a	n/a	75%	66.70%	-8.30%	77.80%	87.50%	9.70%

Note. Percent of providers answering each question correctly. Percent improvement is calculated by subtracting the pre-survey percent correct from the post-survey percent correct.

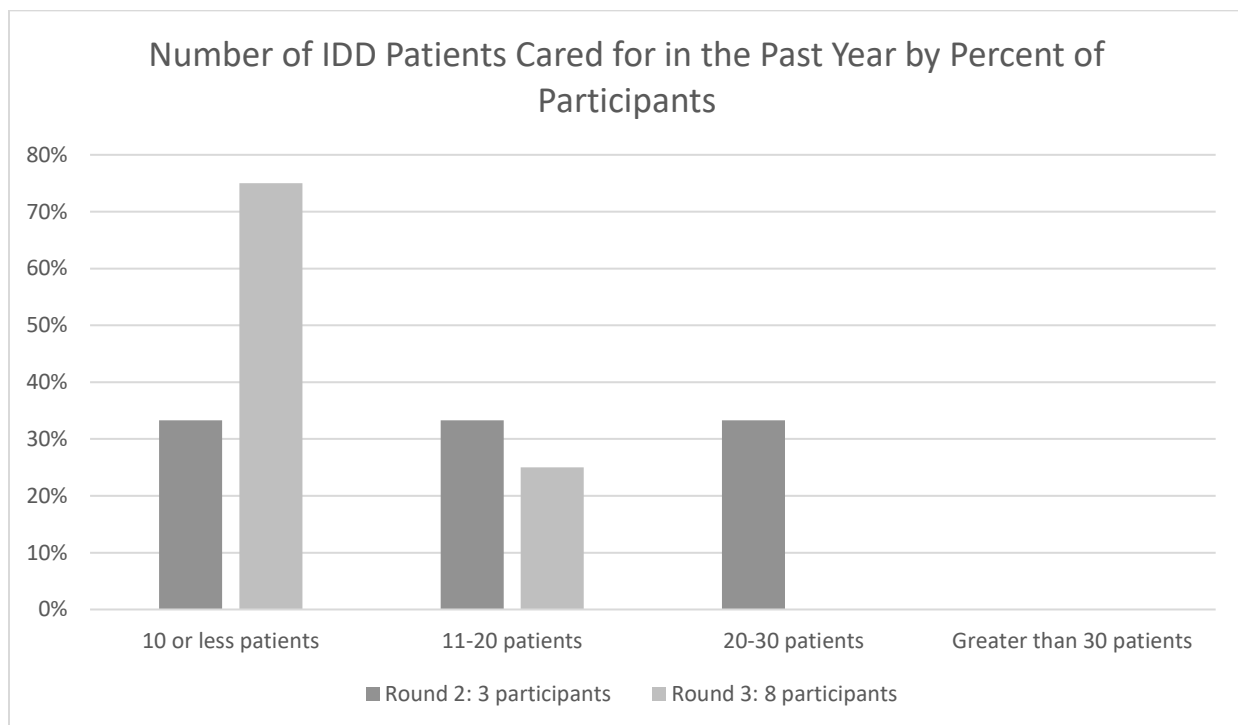
Free-text Answers

Questions 10 and 11 on the post-survey requested free-text answers. Participants could provide qualitative comments on how the training improved their comfort level in caring for patients with IDD and how the training could be improved for future providers. There was no post-survey completed in Round one by any of the participants, so no free-text answers were obtained. Round two had three responses for each question and Round three had eight responses for each question. Those responses are listed in Appendix D.

Number of IDD Patients in the Past Year

The number of IDD patients cared for by the survey participants in the past year is information that was specifically requested by Special Olympics North Carolina to gauge how much experience participants had with these patients. This question was only on the post-survey and participants had the option to choose 10 or less patients, 11-20 patients, 21-30 patients, or greater than 30 patients. Since no post-surveys were completed in round one, no data was collected. Round two had a total of three responses and round three had eight responses. Those results are displayed below in Figure 1.

Figure 1



Note. Percent of survey participants for each category of IDD patient exposure for the past year demonstrated for round two and round three of intervention.

Expected Versus Actual Results

This improvement project aimed to result in an improvement of the participants' comfort level with caring for IDD patients. It was also expected that there would be an improvement in the percent of correct answers of the content questions. Modifications were made to the intervention between each round of implementation, so it was expected that subsequent rounds would produce a greater level of improvement in all questions.

For round one, there was no improvement noted because no providers completed the training and both surveys. However, feedback via email was used to recreate the training in a more condensed version. Round two demonstrated improvement in most areas of comfort, but the two weakest areas (informed consent and behavioral crisis management) were covered more thoroughly in the next modification. For content questions, there was an improvement for question eight, no improvement for questions nine or 10 because all responses were correct on both surveys and a negative improvement for question 11. It is unclear why there were fewer correct responses for this question, but the order of slides was modified to provide more focus on communication. Round three had the greatest number of participants, providing more generalizable results. There was an improvement in comfort level for all areas. In addition, there was more improvement in comfort with informed consent and behavioral crisis management in round three as compared to round two. All content questions demonstrated improvement except for question eight, which had 100% correct responses on both the pre-survey and post-survey.

Outcomes and Process Data

The outcome measure that this project intended to achieve is improved access to care and quality for Spanish-speaking Special Olympics athletes by improving the process in which athletes find primary and specialty care providers that are trained to manage IDD patients. Due to

time constraints, measuring improvement in access to care was not attainable with this project. This data may come with years of observation, whereas this particular project only took place over the course of five months.

Instead, process data was evaluated. This project focused on improving the quality of care by increasing providers' comfort level and understanding of IDD medical care with a simple training video. The project also intended to improve the referral process from Special Olympics MedFest events to either primary care or specialty care based on the athlete's needs. Ideally, all providers in a given county or region would be trained using the tested video. These providers would then be listed on a Referral Tool that includes location, specialty, insurance information, language translation services, and whether or not the provider has participated in the IDD training program (see Appendix C). The Referral Tool can then be utilized by those working at MedFest events to facilitate access and continuity of care for this population. Unfortunately, because there was not a significant response from Chatham County providers, a Referral Tool was not able to be created for Chatham County within the time constraints of this project. The site champion opted to test the training video on providers outside of the county by using North Carolina healthcare providers who have a relationship with SONC to focus on this aspect of the project. For these reasons, a Referral Tool Template has been created by the DNP student to use in Chatham County or other regions when more training has been completed (see Appendix C).

Discussion of Major Findings

Overall, it was found that the training video created by the DNP student did increase comfort level with caring for IDD patients. Even in instances when groups of providers had less experience with the IDD population, participants noted that the training video increased their comfort with various aspects of care. Each modification of the training correlated with an

improvement in provider understanding and comfort, thus indicating that the modifications were useful. The training should be tested on larger groups of providers to verify the findings, but preliminary results positively reflect the goals of this project.

Section V. Interpretation and Implications

Cost-Benefit Analysis

Project costs

The most costly facet of this project was the time required for the recruitment of participants and creating the training. Over 50 hours were spent by the DNP student calling offices, explaining the project in detail to providers or office managers, and sending emails to providers to gather participants. Another 75 hours were spent creating and modifying the training video. Since this project was completed by a student, this time did not require financial reimbursement. However, this time burden may need to be considered if a Special Olympics employee was to continue the project. An employee making \$15 per hour, for example, would create a cost of \$1,875 for this portion of the project. Additional funds would then be required to continue paying the employee for analysis of results, creation of the Referral Tool, and continued dissemination to other areas of North Carolina.

This project also required the use of a computer to build the survey and retrieve results. An employee would need to be provided with a computer, which would cost about \$350 for a basic computer. The DNP student utilized Google Forms to create the survey which is free to use with a Gmail account. Other survey tools may be considered, which would require additional funds.

While there was no monetary budget for this project, the possibility of future investment in this initiative was discussed with the Special Olympics site champion. The amount of the future budget has not been finalized at this time. This money would most likely be used as a financial incentive for providers and offices to participate in the training since gathering training participants was one of the most challenging aspects of this project.

Project Benefits

The major benefit of this project was the likely increase in quality of care for IDD patients by increasing provider comfort level with the training video. As discussed previously, the video did increase the comfort level for those who watched it as evidence by the survey results.

The project has the added ability to increase the quality of care by simplifying the referral process from once yearly MedFest events to regular and reliable primary care and specialty care. While this aspect of the project has not been completed in its entirety for the Chatham County community, the Referral Tool Template may be used when there has been a more complete distribution of the training program in this area. The goal is for future DNP students or employees of Special Olympics North Carolina to distribute the training video to providers in Chatham County and then include those providers on the Referral Tool for use at MedFest events. Two DNP students from East Carolina University will be working to continue this project in the next semester. The Referral Tool can be replicated in other communities using the template to benefit the quality of care for IDD patients throughout the state. The use of this tool also benefits the Spanish-speaking community (and all communities) by referring patients and their families to healthcare providers that suit their individual needs, be it Spanish interpretation, location, or insurance acceptance. Given the healthcare disparities that affect the Spanish-speaking population as discussed previously, finding appropriate healthcare providers is key to eliminating these gaps in care.

Overall Return on Investment

Overall there was a good return on investment. Even in the preliminary stages of this project, providers report and increase in their comfort levels in caring for IDD patients.

Continuing to disseminate this project to more providers will only increase the quality of care that patients living with IDD receive. Further development of the Referral Tool for MedFest events will also increase quality and continuity of care. With consistent and appropriate care for IDD patients, there is an opportunity to decrease costly healthcare spending like chronic illnesses and emergency room visits. This, then, reduces the healthcare associated cost to both the patient and the healthcare system. Another added benefit is the comfort that the families and caregivers of those living with IDD will have knowing that their healthcare provider does express comfort and competence for treating this unique population. The health disparities that exist within the Hispanic and the IDD communities will benefit from this investment. If more money, time, or people can be utilized in this project, an even greater impact can be made on these communities.

Resource Management

Organizational Resources

Some resources were provided by the partnering organization, Special Olympics North Carolina, to facilitate success in this project. First, Special Olympics sanctioned training modules were used to create the training video that was sent to providers. This was helpful in that the information was already approved by Special Olympics administration. With each modification made to the training video, Special Olympics administrators and the site champion were available to provide feedback and approval before releasing it to participants.

When there was not enough participation from Chatham County providers, the site champion was able to provide the contact information for physicians, nurse practitioners, and physician assistants from across the state. This resource was useful in that the efficacy of the training video was able to be surveyed and improved even if the providers were not all from the same area.

Organizational Needs

The greatest need for this project is a more effective way of gaining provider support and participation. An incentive program funded or provided by Special Olympics North Carolina, be it financial or otherwise, would be useful in encouraging providers from a given community to make the goals of this project a reality. Several incentive ideas were discussed with the site champion including a financial incentive, a badge for the office website from Special Olympics, or a poster to hang in the office demonstrating partnership with Special Olympics and the IDD community.

This project aims to eliminate the disparities of those with IDD who are also Spanish-speaking, so another important need is greater outreach to the Spanish-speaking community. This may include marketing for MedFest events in Spanish or Spanish translation services at MedFest events.

Unused Organizational Resources

Toward the end of the intervention, the site champion informed the DNP student that some budget had become available to invest in this project. This money would have most likely been used as an incentive for providers. However, since the project was near completion, this funding was not utilized by this student. The willingness of Special Olympics to invest in this initiative is an indicator of its success. Both the foundational project described in this paper plus the funds may be used in the future for further development of this project. The amount of financial input by Special Olympics was not finalized.

Implications of the Findings

The analysis of this project indicated that the newly-produced training video improved provider comfort with various aspects of caring for patients with IDD. This increase in comfort

then translates to several positive implications for patients, nursing practice, and the healthcare system as a whole.

Implications for Patients

This training video has a positive effect on patient care in that it ensures the providers in their geographic area have a basic understanding of differences in IDD patients as compared to typical patients. These differences in care are discussed in detail in the training video, including communication techniques, common health issues, behavioral crisis management, and implications of good healthcare for this population. Several other resources about the management of IDD patients are provided at the end of the video. Given that providers may only rarely care for individuals with IDD, the resources offer quick access to information to optimize care.

The referral tool also has positive implications in that it prioritizes the individual needs of patients to ensure they are getting affordable, appropriate, and consistent care. Not only does the referral tool and training video aim to improve care for IDD patients, but special attention was paid to the needs of those in the Hispanic community as well. Finding care with language translation for those who are Spanish-speaking or have Spanish-speaking caregivers will reduce the many disparities that afflict these communities.

Implications for Nursing Practice

This intervention targeted all healthcare providers, not nursing specifically. However, it emphasizes the importance of inclusivity and access to healthcare, which the role of nurse practitioner seeks to improve. The intervention, then, implies that nurse practitioners can be extremely valuable in working to eliminate the disparities affecting these athletes.

Implications for Healthcare System

This research and intervention brought to light several implications for the healthcare system. First, there is a known inadequacy of education from medical schools and PA/NP programs for the care and management of the IDD population (American Academy of Developmental Medicine & Dentistry, n.d.). Intellectual and developmental disabilities are a mainstay of training and education in pediatrics, but the demographic of this population is ever-changing. People with disabilities are now living longer lives requiring adult care, but the education programs have not adapted to this demographic change. While this short training video can increase comfort in providers, these disparities may be further reduced with more training at this level.

This intervention also demonstrated that those in vulnerable populations require assistance navigating the complicated healthcare system. Those with disabilities or those who are primarily Spanish-speaking may not understand how, where, or why to get medical care. Understanding treatment plans, following through with referrals, taking medications as prescribed, and navigating insurance issues may be difficult for anyone. However, a language or intellectual barrier will make this navigation even more challenging and may be detrimental for those who belong to both groups. The development and usage of the Referral Tool will help to facilitate this navigation.

Sustainability

Continuation of Project

Special Olympics North Carolina does have plans to continue to develop this project in Chatham County and other regions of North Carolina. By utilizing future DNP students, this project may continue without the added cost of paying an employee. Two DNP students from

East Carolina University plan to expand on the existing project through April 2022. Therefore, the funds that have become available more recently may be used as a financial incentive for providers or other sustainability needs.

Barriers to Sustainability

The main barrier to the sustainability and success of this project is community support and participation. Without provider participation, the Referral Tool cannot be completed and the objectives of this project cannot be achieved. The aforementioned funds will hopefully facilitate this participation and thus produce a program that improves the care of those with intellectual and developmental disabilities, especially those in the Spanish-speaking community. Also, it is believed that the exclusively virtual nature of this project due to COVID-19 protocols was a hindrance to gaining support from local providers. If these protocols remain in place, it may be a barrier to sustainability.

Dissemination Plan

This project was disseminated to both Special Olympics North Carolina and East Carolina University College of Nursing, the two partnering institutions that facilitated this project. The Special Olympics North Carolina presentation included Ellen Fahey, the site champion, along with other Special Olympics North Carolina administrators such as the President/CEO and Vice President. The Special Olympics International online training director was also present since the main focus of this project was the evaluation of a new training module. Other community resources were present such as MedFest clinical directors and community health department leaders. The dissemination was held April 14, 2021 as a Zoom meeting due to COVID-19 restrictions. With hope, this meeting will produce meaningful conversation about sustainability so that the project may continue within this organization.

The dissemination at East Carolina University College of Nursing took place on April 6, 2021. This was an online poster presentation with a question-and-answer session following. Dr. Jan Tillman, faculty advisor for this project, was present as well as other faculty and peers from East Carolina University. Site champion Ellen Fahey was also present. The purpose of this presentation was to explain this particular project and plans for sustainability as a means for improving the healthcare system with the doctorate of nursing practice.

Section VI. Conclusion

Limitations

There were several limitations noted during the implementation of this project. The first limitation was the low number of providers surveyed. While the results did demonstrate an increase in provider comfort with IDD patient care after viewing the training video, this information would be more generalizable with more participants. There was also significant variation in the level of exposure (determined by number of IDD patients cared for in the past year) and education of IDD care amongst providers, so this may also have a larger impact due to the limited number of results. Because the participation was limited, there was not a great variety in the subspecialty of providers. Nine providers were primary care, one pediatric, one pulmonary, one ophthalmology, and one emergency medicine. It is unclear if certain specialties correlate with increased comfort level since the surveys were anonymous, but this information may be useful for future study. The goal, of course, is to create training that is valuable for providers of any level of IDD exposure and any specialty so that all are prepared when this patient comes into their care. More specialties need to be trained in a given geographic area to make the referral tool functional.

Another limitation was the inability to include medical recommendations in the training video. Since Special Olympics is not a medical organization, they could not support a video that contained direct medical practice recommendations. Several qualitative feedback comments requested more direct recommendations, especially in regards to certain specialties and pharmacologic recommendations. Partnering with a medical organization or school in the future may alleviate this limitation. Until that can happen, there are several listed resources in the video to direct providers to the appropriate channels to obtain the information they desire.

Finally, a great limitation of this project was the fact that the DNP student was unable to discuss the benefits of this project in a face-to-face manner due to COVID-19 restrictions. It is felt that if the DNP student were able to enter into offices to talk directly with providers, there would have been more participation.

Recommendations for Others

Future Student Research

Several DNP student projects are recommended after the close of this project to continue to increase access to care and quality of care for those living with IDD in the Spanish-speaking community. First, the same project design can be implemented to a greater number and variety of providers to ensure that the training video is ideal for all specialties and levels of understanding of IDD care. With more incentive programs (as mentioned previously) and more community support, greater participation and diversity can be anticipated. This will ensure that Special Olympics can confidently disseminate the video to all of North Carolina, the United States, or the world.

A second project idea is to focus on a given geographical area to train the providers and more thoroughly develop a Referral Tool for use in that area's MedFest event. This would include community cooperation and evaluation of the area's resources for the athletes. It would benefit communities with higher percentages of Hispanic residents to adequately advertise for Medfest in both English and Spanish, and illustrate the focus in finding athletes care that is appropriate for their culture, language, and financial needs.

A third idea is to more closely focus on the Spanish-speaking population to make MedFest friendly to these athletes and their families. This may include offering Spanish interpreters at MedFest events (in-person or virtual), advertisements for MedFest in Spanish and

displayed in ways that those within this community would have access to the information, or training MedFest providers to understand differences in culture that they may experience when caring for these athletes and families. These three recommendations may serve as a starting point for future students, but there may also be many more ways to continue this project to eliminate the disparities seen with both the IDD community and the Spanish-speaking community.

Each of these projects may be completed by a single student or a group of students depending on the depth of the project. For example, a single student focusing the training on a geographical area for Referral Tool development may be sufficient if he or she knows the area well. However, since distribution and participation was a major challenge of this foundational project, two or more students may lead to better results. Future students may use recommendations from Special Olympics to decide the number of students that should work on a given project.

Recommendations for Special Olympics

Special Olympics North Carolina and Special Olympics International will also play a large role in making sure this project can be optimized to help these athletes achieve better healthcare. For one, after a Referral Tool is created for a given geographical area, Special Olympics may disseminate the Referral Tool further than simply using it for MedFest events. This may mean disseminating to primary care or pediatric providers as an easy reference to get their patients appropriate specialty care. This will give the intervention an even broader reach.

As discussed previously, incentives for participation provided by Special Olympics can facilitate the success of this initiative. This may present as financial incentives for practices, a badge in-office or on the practice's website that demonstrates that the providers have completed the training, or continuing education (CE) credits for completing the training. All of these

options may increase participation, which was one of the greatest limitations of this project. Without near-universal training in a given area, the proposed increase in accessibility and quality of care for IDD patients via the Referral Tool is not possible.

Finally, if Special Olympics partnered with a medical organization or school, there would be an opportunity to provide direct medical and/or pharmacological recommendations in the training. Medical practice information could then be included in this training video or as a separate training video. Another idea is for contact information of a medical partner who can answer questions for those participating in training to be provided at the close of the training video. This more specific practice information was frequently requested by providers in the qualitative answers of the post-survey, thus indicating that this would increase the success of the project.

Recommendations Further Study

The recommendations for further study of this intervention are to continue to test the newly-produced training program with providers to elicit the effectiveness of the training for increasing provider comfort in caring for IDD patients. It is vital to continue to make modifications to the training as needed. This will create a sound knowledgebase and foundational entrée to behaviors for healthcare providers regardless of specialty, location, training, or current knowledge of IDD care. Once the training video is found to be effective and applicable, the goal is to work with communities to achieve universal training of healthcare providers and disseminate the Referral Tool.

Finally, a long term study of outcome measures of change in access to care and quality of care for athletes and other IDD community members before and after training and Referral Tool distribution will further solidify this project. This may be performed for all IDD community

members or specifically Spanish-speaking community members. This study may measure the number of community members attending MedFest, the number of times Referral Tool was used, patient and family experience with providers after training, patient and family experience with system navigation with Referral Tool, and many more. These outcome measures will need to be measured over months to years to truly understand the project impact but will be helpful for quality improvement measurement and modification.

Overall Conclusions

Overall, this DNP project was a success in that the newly-produced training video did demonstrate an improvement in provider comfort with caring for IDD patients. The process measures were, therefore, achieved. This indicates that the overall outcome measures of improved access to care and quality of care for those with intellectual and developmental disabilities will be achieved over time. A Referral Tool template was also successfully created for future use (See Appendix C). This project may have already improved the healthcare of some people living with intellectual and developmental disabilities, but more importantly, it has created a base for the development of future projects to further eliminate the disparities for those in both the IDD and Spanish-speaking communities.

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Appendix A

Comfort with Intellectually and Developmentally Disabled Patients (Pre-survey)

1. How comfortable are you formulating a plan of care for someone with IDD
 - a. Very uncomfortable
 - b. Somewhat uncomfortable
 - c. Neither comfortable nor uncomfortable
 - d. Somewhat comfortable
 - e. Very comfortable
2. How comfortable are you with appropriate ways to communicate with IDD patients?
 - a. Very uncomfortable
 - b. Somewhat uncomfortable
 - c. Neither comfortable nor uncomfortable
 - d. Somewhat comfortable
 - e. Very comfortable
3. How comfortable are you with informed consent for IDD patients?
 - a. Very uncomfortable
 - b. Somewhat uncomfortable
 - c. Neither comfortable nor uncomfortable
 - d. Somewhat comfortable
 - e. Very comfortable
4. How comfortable are you handling a behavioral crisis for an IDD patient?
 - a. Very uncomfortable
 - b. Somewhat uncomfortable

- c.** Neither comfortable nor uncomfortable
 - d.** Somewhat comfortable
 - e.** Very comfortable
- 5.** How comfortable are you finding appropriate resources for care of IDD patients?
 - a.** Very uncomfortable
 - b.** Somewhat uncomfortable
 - c.** Neither comfortable nor uncomfortable
 - d.** Somewhat comfortable
 - e.** Very comfortable
- 6.** All of the following are barriers to health for people with IDD EXCEPT:
 - a.** Diagnostic overshadowing
 - b.** Insufficient provider training
 - c.** Unconscious bias, stigmatization, and discrimination
 - d.** Number of healthcare providers in the US
- 7.** True or False: Neurodevelopmental disorders may result in intellectual disability, seizure disorder, psychiatric disturbances, communication difficulties, and sensory deficits.
These neurodevelopmental disorders are caused strictly by genetic defects.
 - a.** True
 - b.** False
- 8.** In addition to the neurological system, a neurodevelopmental disorder may affect the development of which other system(s)?
 - a.** Cardiopulmonary system
 - b.** Musculoskeletal system

- c.** Gastrointestinal system
 - d.** Endocrine system
 - e.** All of the above
- 9.** The best way to communicate with a patient with IDD is to:
 - a.** Talk to their caregiver first to identify major problems, then address the patient
 - b.** Assume the patient cannot communicate, proceed with the assessment without addressing patient
 - c.** Address the patient as you would any other patient of that age, then the caregiver can fill in information as needed
 - d.** None of the above are appropriate

Appendix B

Comfort with Intellectually and Developmentally Disabled Patients (Post-survey)

- 1.** How comfortable are you formulating a plan of care for someone with IDD
 - a. Very uncomfortable
 - b. Somewhat uncomfortable
 - c. Neither comfortable nor uncomfortable
 - d. Somewhat comfortable
 - e. Very comfortable

- 2.** How comfortable are you with appropriate ways to communicate with IDD patients?
 - a. Very uncomfortable
 - b. Somewhat uncomfortable
 - c. Neither comfortable nor uncomfortable
 - d. Somewhat comfortable
 - e. Very comfortable

- 3.** How comfortable are you with informed consent for IDD patients?
 - a. Very uncomfortable
 - b. Somewhat uncomfortable
 - c. Neither comfortable nor uncomfortable
 - d. Somewhat comfortable
 - e. Very comfortable

- 4.** How comfortable are you handling a behavioral crisis for an IDD patient?
 - a. Very uncomfortable
 - b. Somewhat uncomfortable

- c.** Neither comfortable nor uncomfortable
 - d.** Somewhat comfortable
 - e.** Very comfortable
- 5.** How comfortable are you finding appropriate resources for care of IDD patients?
 - a.** Very uncomfortable
 - b.** Somewhat uncomfortable
 - c.** Neither comfortable nor uncomfortable
 - d.** Somewhat comfortable
 - e.** Very comfortable
- 6.** All of the following are barriers to health for people with IDD EXCEPT:
 - a.** Diagnostic overshadowing
 - b.** Insufficient provider training
 - c.** Unconscious bias, stigmatization, and discrimination
 - d.** Number of healthcare providers in the US
- 7.** True or False: Neurodevelopmental disorders may result in intellectual disability, seizure disorder, psychiatric disturbances, communication difficulties, and sensory deficits.
These neurodevelopmental disorders are caused strictly by genetic defects.
 - a.** True
 - b.** False
- 8.** In addition to the neurological system, a neurodevelopmental disorder may affect the development of which other system(s)?
 - a.** Cardiopulmonary system
 - b.** Musculoskeletal system

- c.** Gastrointestinal system
 - d.** Endocrine system
 - e.** All of the above
- 9.** The best way to communicate with a patient with IDD is to:
 - a.** Talk to their caregiver first to identify major problems, then address the patient
 - b.** Assume the patient cannot communicate, proceed with the assessment without addressing patient
 - c.** Address the patient as you would any other patient of that age, then the caregiver can fill in information as needed
 - d.** None of the above are appropriate
- 10.** Approximately how many patients with IDD have you cared for in the past year?
 - a.** 10 or less patients
 - b.** 11-20 patients
 - c.** 21-30 patients
 - d.** Greater than 30 patients
- 11.** How did this training increase your comfort with caring for IDD patients?
- 12.** How could this training be improved to facilitate more comfort with caring for IDD patients?

Appendix D

Free-text Responses from Post-Survey

	Round 2	Round 3
How did this training increase your comfort with caring for IDD patients?	<ul style="list-style-type: none"> • IT gave tips on communicating with patients and their family. "person first" • It was slightly helpful. • It amplified things that I was already aware of. 	<ul style="list-style-type: none"> • Additional resources in the training will be helpful • Review of the things to look for • Giving simple, yet effective ways to best communicate with IDD patients. • Provided additional helpful resources • I found the resources listed to be helpful and the statistics mentioned about the lack of care provided helpful as it indicates paying closer attention to all systems important. • Great reminders and helpful tips • Introduced me to some resources I didn't know about • Much more comfortable. I do not see many patients that fall into this category but the education was insightful and informative.

	Round 2	Round 3
How could this training be improved to facilitate more comfort with caring for IDD patients?	<ul style="list-style-type: none"> • Perhaps examples of situation for health care providers. Eventually make specialty specific tips. I am an ophthalmologist and will give a lecture on tips for examining and treating this pt population. • More focus on resources available for patients and maybe a separate video explaining how to obtain consent for these types of patients. 	<ul style="list-style-type: none"> • An additional module with case studies would be great. I think the short basic training should stay as it is presented here. • Increase access to other providers to this education. • Some examples of scripts to use with patients with IDD and their caregivers • Maybe some role playing examples with real people

Round 2**Round 3**

How could this training be improved to facilitate more comfort with caring for IDD patients? (cont.)

- I think the training module is very good in the current format. Brief and concise is best when trying to fit training/CME around busy clinic and personal schedules.

- I thought this was well scripted and effectively communicated. Again, the resources provided are extremely helpful and appreciated.
- NA
- The training was comprehensive.
- Showing real life scenarios with examples of how to communicate with IDD patients
- An additional module with case studies would be great. I think the short basic training should stay as it is presented here.

Appendix E

Doctor of Nursing Practice Essentials

	Description	Demonstration of Knowledge
Essential I <i>Scientific Underpinning for Practice</i>	<p>Competency – Analyzes and uses information to develop practice</p> <p>Competency -Integrates knowledge from humanities and science into context of nursing</p> <p>Competency -Translates research to improve practice</p> <p>Competency -Integrates research, theory, and practice to develop new approaches toward improved practice and outcomes</p>	<p>Researched and analyzed current data to develop an intervention to improve care of those with IDD in the Spanish-speaking community. Through the extensive study of research, theory, and current practices, the intervention was created.</p>
Essential II <i>Organizational & Systems Leadership for Quality Improvement & Systems Thinking</i>	<p>Competency –Develops and evaluates practice based on science and integrates policy and humanities</p> <p>Competency –Assumes and ensures accountability for quality care and patient safety</p> <p>Competency -Demonstrates critical and reflective thinking</p> <p>Competency -Advocates for improved quality, access, and cost of health care; monitors costs and budgets</p> <p>Competency -Develops and implements innovations incorporating principles of change</p> <p>Competency - Effectively communicates practice knowledge in writing and orally to improve quality</p> <p>Competency - Develops and evaluates strategies to manage ethical dilemmas in patient care and within health care delivery systems</p>	<p>Project specifically functioned to improve access and quality of care. Evaluated current training practices and used past research to adapt training to more adequately serve the IDD and Spanish-speaking populations. Aligned with Healthy People 2020 initiatives and Triple Aim framework. Communicated with project partner and participants via email and telephone.</p>
Essential III <i>Clinical Scholarship & Analytical Methods for Evidence-Based Practice</i>	<p>Competency - Critically analyzes literature to determine best practices</p> <p>Competency - Implements evaluation processes to measure process and patient outcomes</p> <p>Competency - Designs and implements quality improvement strategies to promote safety, efficiency, and equitable quality care for patients</p> <p>Competency - Applies knowledge to develop practice guidelines</p> <p>Competency - Uses informatics to identify, analyze, and predict best practice and patient outcomes</p> <p>Competency - Collaborate in research and disseminate findings</p>	<p>Literature review of communication improvement for Spanish-speaking population, IDD population and Spanish-speaking IDD population performed and analyzed for current improvement practices. Intervention was developed based on this current knowledge. Process measures and outcome measures defined. This quality improvement project successfully improved provider comfort with IDD care, thus improving safety, efficiency, and equitable quality care for these patients.</p>

	Description	Demonstration of Knowledge
Essential IV <i>Information Systems – Technology & Patient Care Technology for the Improvement & Transformation of Health Care</i>	<p>Competency - Design/select and utilize software to analyze practice and consumer information systems that can improve the delivery & quality of care</p> <p>Competency - Analyze and operationalize patient care technologies</p> <p>Competency - Evaluate technology regarding ethics, efficiency and accuracy</p> <p>Competency - Evaluates systems of care using health information technologies</p>	Utilized software systems such as Powerpoint, YouTube, and Google Forms to create training and survey providers on the efficacy of training. Evaluated and improved upon the current online training system created by Special Olympics International.
Essential V <i>Health Care Policy of Advocacy in Health Care</i>	<p>Competency- Analyzes health policy from the perspective of patients, nursing and other stakeholders</p> <p>Competency – Provides leadership in developing and implementing health policy</p> <p>Competency –Influences policymakers, formally and informally, in local and global settings</p> <p>Competency – Educates stakeholders regarding policy</p> <p>Competency – Advocates for nursing within the policy arena</p> <p>Competency- Participates in policy agendas that assist with finance, regulation and health care delivery</p> <p>Competency – Advocates for equitable and ethical health care</p>	Researched current healthcare disparities of those living with IDD and in the Spanish-speaking community. The project worked to improve current policies and procedures through Special Olympics to increase quality and access to care for these patients based on this research. Also completed CITI modules to ensure no IRB was required and that patients were treated ethically.
Essential VI <i>Interprofessional Collaboration for Improving Patient & Population Health Outcomes</i>	<p>Competency- Uses effective collaboration and communication to develop and implement practice, policy, standards of care, and scholarship</p> <p>Competency – Provide leadership to interprofessional care teams</p> <p>Competency – Consult intraprofessionally and interprofessionally to develop systems of care in complex settings</p>	Collaborated with professionals within the Special Olympics organization as well as healthcare professionals within my community and beyond to get feedback on the developed training. These professionals included physicians, nurse practitioners, physician assistants, registered dieticians, and registered nurses. Several healthcare specialties were also represented within these groups. Feedback from these participants allowed me to create a training that could be used for all providers to help those with IDD not only get better care, but also navigate a complex healthcare system.
Essential VII <i>Clinical Prevention & Population Health for Improving the Nation's Health</i>	<p>Competency- Integrates epidemiology, biostatistics, and data to facilitate individual and population health care delivery</p> <p>Competency – Synthesizes information & cultural competency to develop & use health promotion/disease prevention strategies to address gaps in care</p> <p>Competency – Evaluates and implements change strategies of models of health care delivery to improve quality and address diversity</p>	This project specifically worked to address healthcare disparities in the IDD and Spanish-speaking communities. Cultural competency was used to understand the disparities found in literature and promote regular and reliable primary care and specialty care for those within this special community.

	Description	Demonstration of Knowledge
<p>Essential VIII <i>Advanced Nursing Practice</i></p>	<p>Competency- Melds diversity & cultural sensitivity to conduct systematic assessment of health parameters in varied settings Competency – Design, implement & evaluate nursing interventions to promote quality Competency – Develop & maintain patient relationships Competency –Demonstrate advanced clinical judgment and systematic thoughts to improve patient outcomes Competency – Mentor and support fellow nurses Competency- Provide support for individuals and systems experiencing change and transitions Competency –Use systems analysis to evaluate practice efficiency, care delivery, fiscal responsibility, ethical responsibility, and quality outcomes measures</p>	<p>Evaluated current knowledge of and comfort with IDD care among healthcare providers and then improved that knowledge and comfort with training video. The Referral Tool template was developed for future projects and will be utilized as a way to address social and cultural issues as a way to find the ideal provider for a particular patient. This project fulfills the ideals of advanced nursing practice in that it seeks to improve quality of care with efficiency, financial responsibility, ethics, and system understanding to get patients in this focus the best care possible to close the gaps identified.</p>