Using Community Health Assessment to Teach and Explore Health Status Disparities

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ABSTRACT
Introduction: *Community health assessment (CHA) is a useful tool for identifying health status disparities at the community level. Developing the skills of master's level public health students to conduct CHA addresses a number of the Association of Schools of Public Health Core competencies for graduate public health education.* ***Teaching Procedures:*** *This article reports on the experience of conducting and analyzing a CHA of disparities in access to autism services among low-income Latinos in Nassau County, NY.* ***Discussion:*** *Conducting a CHA as part of the course helped to illustrate academic concepts, and revealed how disparities in access to services and service provision may ultimately lead to disparities in outcomes for low-income Latino children with ASDs.*

INTRODUCTION

Health status disparities are one of the most important public health challenges facing the United States. Since 2000, addressing health status disparities has been articulated as a key aim of the federal government's Healthy People initiative. The prioritization of health disparities at the federal level, reinforces the importance of focusing on health disparities in both substantive and methods courses developed for master's level public health students (U.S. Department of Health and Human Services, n.d.).

Community health assessment (CHA) is a useful tool for public health workers who want to understand and address health status disparities at the community level. To conduct CHA, public health practitioners identify and examine existing secondary data and then determine if primary data collection is necessary to answer the assessment questions of interest (National Association of County and City Health Officers, n.d.). Often the first step in developing community-based interventions, CHA allows practitioners to develop an understanding of the needs and assets of a community so that subsequent interventions will be consistent with community priorities and capacities. To align

with Healthy People goals and objectives, addressing health status disparities must necessarily be a key area of focus at the community level, therefore, integrating a disparities perspective into community health assessment is essential.

Developing the skills of master's level public health students to design, conduct, and analyze data from a CHA addresses a number of the Association of Schools of Public Health (ASPH) core competencies across domains such as Social and Behavioral Sciences, Informatics, Diversity and Culture, Program Planning, and Systems Thinking (Association of Schools of Public Health, 2006). Additionally, encouraging students to engage with the community and to hear about disparities directly both from those who are experiencing them and those who are engaged in addressing them can be a powerful learning experience.

This article reports on the experience of conducting a CHA of disparities in access to autism spectrum disorder (ASD) services among low-income Latino families in Nassau County, NY as part of a course on CHA. The course on CHA is the first of a three-semester sequence of courses covering CHA, program planning and implementation, and evaluation, taught within a department that was transitioning to a Master of Public Health program. This CHA was integrated into the 14-week semester and took students through the steps in conducting an assessment focused on health disparities. The class was a seminar and included twelve students. The students were in the second semester of their first year of a two-year program.

The students and professor partnered with a local pediatrician (this paper's second author) who specializes in developmental disorders at Nassau University Medical Center, a public teaching hospital that serves low-income residents of Nassau County, NY. The second author's practice includes a number of low-income Latino children with autism. The second author worked collaboratively with the class and the first author (the professor) to help design and conduct the assessment and assisted with logistical issues.

Latinos, ASDs, and Disparities

Autism spectrum disorders may be diagnosed when children face challenges in communication, social interaction, and behavior

(Johnson & Myers, 2007). Early and proper diagnosis of ASDs (prior to age 3) (Centers for Disease Control and Prevention (CDC), n.d.), and timely receipt of behavioral therapies and other tailored services that aim to improve language and communication and to reduce repetitive behaviors, are essential for improving outcomes for children with ASDs (Myers & Johnson, 2007).

In recent years, racial/ethnic and socio-economic disparities in ASD diagnosis, age at diagnosis, service utilization, and outcomes in the United States, particularly with respect to Latinos, have been documented. Latinos have been found to have a lower prevalence of ASDs compared to non-Latinos, both in studies that use active surveillance and parent report. The difference in prevalence is likely due to less diagnosis of the disorder among Latinos, rather than differences in the racial/ethnic distribution of ASDs (CDC, 2012). This is significant because of the importance of early and accurate diagnosis to improve outcomes. Latino parents are also more likely to regard their child's ASD as severe and report less access to services than whites (Liptak et al, 2008). Disparities in diagnosis and access to services among Latinos have been attributed to a number of factors including culture, language barriers, and poverty (Mandell, Listerud, Levy, & Pinto-Martin, 2002; Liptak et al., 2008).

Setting and Context

Nassau County is located on Long Island in New York State and has a population of 1.3 million people. About 14.6% of the population of Nassau County (14.6%), is Hispanic/Latino (U.S. Census Bureau, 2010). Latino families in Nassau County are more likely to live in poverty than families of all races/ethnicities and have a lower median income. (U.S. Census Bureau, 2006-2010a,b & c) Nearly half Nassau County's Latino residents were not born in the United States, and over one-third report speaking English "less than very well (U.S. Census Bureau, 2006-2010c)."

Purpose and CHA Methods

Our purpose in conducting the assessment was two-fold: 1) to assess access to ASD services in Nassau County among low-income Latino families and 2) to train students to conduct a CHA while integrating the perspective of evaluating health disparities. Here, we report on the process of designing, conducting and

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analyzing the assessment and make recommendations for incorporating similar projects into other community assessment courses.

The CHA aimed to identify primary and secondary data sources on ASD service utilization by Latino families; qualitatively assess Latino families' experiences with ASD services in Nassau County and the perspectives of service providers with respect to how well the ASD service provision system in Nassau County is serving low-income Latino families; make recommendations based on our findings for improving service provision to Latino families; and to train students to conduct a community health assessment with a disparities focus.

TEACHING PROCEDURES

Because we aimed to conduct the CHA from start to finish during the course of a 14-week semester, there was significant planning that had to occur prior to the beginning of the semester. This included conducting a literature review on what was known about Latinos and access to ASD services, holding meetings with the second author to clarify the goals and logistics of conducting the assessment, and meetings with leadership at NUMC to determine parameters for collecting data on-site with NUMC patients. Additionally the project had to be submitted for human subjects approval prior to the start of the semester, which meant that the design, protocols, questionnaires and consent forms had to be developed prior to the commencement of classes. Although we wanted students to participate in the design of the CHA we realized that this would not be possible given the need to submit a fully developed and articulated project for human subjects review in time to begin data collection at the mid-point of the semester. The project was reviewed by the Hofstra University Institutional Review Board and found to be exempt.

The integration of a CHA project into the course required a re-design of the course syllabus to be able to cover both course concepts and to integrate the required trainings that would enable the students to become knowledgeable about ASDs, Latinos in Nassau County and to develop the skills to collect and analyze data. Table 1 summarizes the tasks completed by week of the semester.

During the first week of the semester the class session focused on explaining the purpose and uses of CHA and providing background on the project that the students would conduct. The homework assignment for week one was for the students to work in groups to identify all ASD service providers in Nassau County. This would become the basis for the list of service providers we would use to conduct interviews. Readings for the first week included background on CHA and an article on disparities in ASD diagnosis among Latinos.

For week two, students read an example of a CHA that examined health care needs among refugees in San Diego and we continued our discussion of the purpose and use of CHA using this report as an example that both illustrated a mixed-methods approach to conducting CHA, and was rich in relevant content, as it discussed barriers limited English speakers face accessing health care (Brouwer, 2007). Additionally, after a short training on using census data to describe population demographics, homework for the second week of class involved students using data from U.S. census web sites to describe the social and demographic characteristics of the Latino population of Nassau County.

During week three, the second author conducted a training for the students on ASDs and explained the key features of ASDs, their diagnosis, and effective therapies. He also described the social and economic context of the Latino families who have children with ASDs seen at NUMC.

The next week was focused on planning a CHA by developing the purpose, goals and objectives. For homework, students were tasked with working in groups to develop a concise statement of the purpose, goals and objectives of the assessment and to start thinking about the kinds of questions they would ask parents and service providers about the needs of Latino families who have children with ASDs.

As the semester was progressing, the professor took the lead in identifying and requesting data from administrative agencies on the use of publicly funded services for ASDs by Latinos in Nassau County. Since ASD services are administered by several different agencies there is no central agency responsible for reporting these data. We also determined that the data we were primarily interested in, use of

services by race/ethnicity, were not routinely being reported in a publicly accessible format. Therefore, we made data requests to the Nassau County Health Department for data on enrollment in the county Early Intervention program by race/ethnicity and we requested data from the State Department of Health on enrollment in pre-school special education. Additionally, we requested data from the State Education Department on enrollment of Latinos in school-aged special education in Nassau County and also requested data from the New York State Office for Persons with Developmental Disabilities (OPWDD) on the receipt of the Home and Community Based Service (HCBS) Medicaid waiver by race/ethnicity and socio-economic status, which pays for critically important rehabilitative and non-medical services for children. We found that for most of these data sources, we needed to make freedom of information law (FOIL) requests to obtain them.

Aside from the collection of administrative data on use of publicly funded services, the remainder of the assessment called for collecting data through semi-structured interviews with Latino parents of children with ASDs being served at NUMC and through semi-structured interviews with Nassau County service providers. The purpose of interviewing service providers was to understand their perspectives on Latino families' access to and use of ASD services in Nassau County.

We chose semi-structured interviews because their open-ended nature can help to illuminate health issues about which little is known, and provide descriptive data about the social and cultural context of the health issue (Patton, 2002).

During week five, students were trained in following human subjects protocols and seeking informed consent prior to interviewing participants. They were also trained in conducting semi-structured interviews, including reading the questions exactly as written and allowing respondents the time and "space" to answer. The use of probes in open-ended interviewing was also modeled for the students. Finally, students were trained in note taking and the importance of verbatim note taking was stressed since we had neither the funding nor the time to tape and transcribe the semi-structured interviews. During the class session,

students had the opportunity to practice interviewing and note taking and to discuss any challenges they encountered.

Although we had initially planned that students would be involved in interviewing Latino parents at NUMC, we were unable to follow through with this plan due to issues with the site's medical requirements for students. Therefore, two graduate research assistants (one who was fluent in Spanish) and the professor conducted the interviews, with the Spanish-fluent graduate research assistant the lead interviewer and note taker. In a few cases when the Spanish-speaking research assistant was not available, we relied on a hospital interpreter to provide interpretation and the professor conducted the interviews. Notes were taken by the interviewer and typed up immediately following the interview.

During weeks six through eight, the students conducted semi-structured interviews with ASD service providers to learn their perspectives on how well Spanish-speaking families who have children with ASDs are being served in Nassau County, and if the service delivery system might be improved to better meet their needs. Each student was responsible for interviewing two service providers over the phone within a month-long data collection timeframe. Nine service providers agreed to participate.

All service provider interviews took place over the phone, and were conducted by the students. Students were required to take as close to verbatim notes as possible and to write up and submit their interview notes within one day of the interview. Service provider interview questions covered topics such as needs of low-income Latino families, how well needs are being met in Nassau County, and barriers and facilitating factors for accessing services for these families. Providers were also asked for their recommendations to improve service provision to low-income Latino families in Nassau County.

During week nine, students were instructed on how to develop a code book for coding qualitative interviews and their assignment was to develop an initial draft of a codebook for coding the provider and parent interviews. Students were divided into small groups and two groups were responsible for developing a codebook for the provider interviews and the

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other two groups were responsible for developing a draft codebook for the parent interviews. The next step was instruction on how to report and interpret qualitative data, which included discussions of making appropriate inferences from a small sample size. Over the next week, with feedback from the professor, students refined their codebook and coded all of their interviews.

During week eleven, students were tasked with working in small groups to write up a rough draft of their findings. The professor provided written and oral feedback on the rough drafts and final written reports were due during week thirteen. Students were also required to do an oral presentation of their findings to the class and to the second author.

DISCUSSION

Recommendations to include an emphasis on health disparities in health-related coursework are common in the recent public health and medical education literature. Some authors have recommended a focus on addressing bias and stereotyping and analyzing how these viewpoints might play out in the clinical or community setting. Another recommendation is a focus on understanding the complex causes of disparities and possible ways to address them, and still another is to teach cultural competency to future providers as a way of addressing health disparities (Smith et al., 2007). Others have advocated conducting community-based projects, like community health assessment, as a way to learn more directly about how health disparities are experienced in low-income communities and in communities of color (Cené, Peek, Jacobs, & Horowitz, 2010; Selig, Tropiano, & Greene-Moton, 2006).

Conducting a CHA project such as this as part of masters level public health coursework aligns with recommendations in the literature as well as multiple ASPH core competencies. Conducting the project during a 14-week semester presented a number of challenges, but we believe the benefits were substantial and outweighed the challenges. Importantly, the project provided vivid context to class discussions of academic concepts, and tangibly illustrated how disparities in access to services and service provision may ultimately lead to disparities in outcomes for low-income Latino

children with ASDs. The project also allowed for discussion of cultural competency in the provision of public services and the importance of assessing equity in service provision as an aspect of understanding community based health disparities.

For the students, the ability to interact with community providers who work to address health status disparities on a daily basis was invaluable. The second author's participation in the course was a highlight for many. Additionally, conducting the interviews and hearing the stories of service providers who work with low-income Latinos and were of the opinion that Latino families in Nassau County were not being adequately served was a powerful experience for many of the students. They were able to hear directly from providers about the challenges that Latino families face in accessing services including language barriers, transportation, and difficulty accessing public programs—tangibly extending classroom concepts.

Using a qualitative approach to gather data from both parents and providers had benefits and limitations. The benefit of open-ended data collection is that respondents can talk at length about access issues and tell their own stories, which can illuminate key issues. Also, a qualitative approach allows students to engage more deeply with some of the complexities of access barriers as many of the providers explained these in significant detail. From a learning perspective, using a qualitative approach has significant advantages. However, from a research standpoint, having multiple interviewees collecting open-ended data was a challenge. We did not have the funding to tape record interviews and to transcribe them and thus had to rely on variable note-taking skills. A better option might be to use a quantitative survey instrument that would allow for greater control over data quality with multiple data collectors.

Because we had no funding beyond two graduate research assistants, it was challenging to conduct a CHA partially in Spanish since we did not have resources for translating the questionnaire and consent form, and for hiring interpreters. Initially we approached the University's Spanish department to ask if Spanish majors could provide translation but this turned out to not be feasible. Ultimately we

decided to use Google Translate to translate the interview and the consent form, aware that it could have limitations. However, to address possible problems with this method, the Spanish-fluent graduate research assistant back-translated the documents into English and we reviewed her translation and made the necessary corrections. She also tested the final translated study documents on two native speakers. While it is very important for students to understand the logistics of collecting data in a language other than English, it can also be challenging in an unfunded project such as this.

One of the most informative parts of the project was the process of trying to identify and obtain data from administrative agencies on the use of ASD services by Latinos. We found that we had to make direct requests from the responsible agencies because the data we were seeking was not available in published format for Nassau County.

Students were instructed in the idea that data collected by public agencies is often in the public domain and if community or public health workers cannot access data to assess health status disparities through agency issued reports, they can make a freedom of information law (FOIL) request to try to obtain the data, if it exists. We made 3 separate FOIL requests, all of which were granted, at least in part. From this process we learned about important limits to the data that public agencies are routinely collecting and reporting on use of ASD services both by race/ethnicity and by socio-economic status.

An instructive class project that would be less involved than this one could be simply identifying and contacting responsible agencies and requesting local or state data on access to services for children with ASDs or other disabilities (e.g. early intervention, Medicaid waiver) by race ethnicity and socio-economic status. If the data are not made available, students can learn the process of making a FOIL request to obtain them. The students can thereby evaluate the adequacy of routinely collected data for determining whether or not services are equitably distributed by race/ethnicity or socio-economic status. This idea could also be applied to data requests for public health data that might shed light on local disparities in health status outcomes.

Use of Findings

Because of the small sample size for both the parent and provider interviews, we view the findings from the project as a starting point for understanding access barriers for low-income Latino families in Nassau County. Extending the project over multiple semesters and increasing the amount of data collected would provide more parent and provider data from which to make recommendations.

A report of findings was distributed to key community leaders working with the Latino community. We also presented the findings to the local Alliance for Latinos with Disabilities. This group has formulated a plan to work on some key recommendations of the report such as increasing the hiring of bilingual staff in key agencies serving Latinos with ASDs. Additionally, training workshops for agencies that serve Latino families have been developed on how to access the OPWDD HCBS waiver.

In summary, involving students in a CHA project specifically focused on evaluating disparities can be a worthwhile learning experience that touches on a number of the ASPH domains and competencies for graduate public health programs. If the project is linked to the interests of providers in the community who may be able to use the findings, coursework can contribute to the process of addressing health status disparities.

REFERENCES

Association of Schools of Public Health. (August 2006). MPH Core Competency Model, Final Version 2.3. Retrieved from http://www.uic.edu/sph/prepare/courses/chsc400/syllabus/mphcorecomp.pdf.

Brouwer, K. (June 18, 2007). Assessment of Community Member Attitudes Toward Health Needs of Refugees in San Diego Draft Report. Retrieved from http://www.sdcounty.ca.gov/hhsa/programs/phs/documents/RefugeeHealthAssessment%28UCSD%29-2007.pdf

Cené, C., Peek, M., Jacobs, E., & Horowitz, C. (2010). Community-based teaching about health disparities: combining education, scholarship, and community service. *Journal of General Internal Medicine*, 25 (Suppl), 2S130-S135. doi:10.1007/s11606-009-1214-3

Centers for Disease Control and Prevention (CDC). (n.d.). Autism Spectrum Disorders, Screening and Diagnosis for Healthcare Providers. Retrieved from http://www.cdc.gov/ncbddd/autism/hcp-screening.html#1.

Centers for Disease Control and Prevention (CDC). (2012). Prevalence of autism spectrum disorders--Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008. *Morbidity and Mortality Weekly Report.* Surveillance Summaries (Washington, D.C.: 2002), 61(3), 1-19.

Johnson, C., & Myers, S. (2007). Identification and evaluation of children with autism spectrum disorders. *Pediatrics*, 120(5), 1183-1215.

Liptak, G., Benzoni, L., Mruzek, D., Nolan, K., Thingvoll, M., Wade, C., & Fryer, G. (2008). Disparities in diagnosis and access to health services for children with autism: data from the National Survey of Children's Health. *Journal of Developmental and Behavioral Pediatrics*, 29(3), 152-160. doi:10.1097/DBP.0b013e318165c7a0

Mandell, D., Listerud, J., Levy, S., & Pinto-Martin, J. (2002). Race differences in the age at diagnosis among medicaid-eligible children with autism. *Journal of the American Academy of Child and Adolescent Psychiatry*, 41(12), 1447-1453.

Myers, S., & Johnson, C. (2007). Management of children with autism spectrum disorders. *Pediatrics*, 120(5), 1162-1182.

National Association of County and City Health Officers (n.d.). Definitions of Community Health Assessments (CHAs) and Community Health Improvement Plans (CHIPs). Retrieved from http://www.naccho.org/topics/infrastructure/community-health-assessment-and-improvement-planning/upload/Definitions.pdf.

Patton, M.Q. (2002). Qualitative Research and Evaluation Methods, 3rd edition. Thousand Oaks, CA: Sage Publications.

Selig, S., Tropiano, E., & Greene-Moton, E. (2006). Teaching cultural competence to reduce health disparities. *Health Promotion Practice*, 7(3 Suppl), 247S-255S.

Smith, W., Betancourt, J., Wynia, M., Bussey-Jones, J., Stone, V., Phillips, C., & Bowles, J. (2007). Recommendations for teaching about racial and ethnic disparities in health and health care. *Annals of Internal Medicine*, 147(9), 654-665.

U.S. Census Bureau. (2010). American Fact Finder Demographic Profile Nassau County, 2010. Retrieved from http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk.

U.S. Census Bureau. (2006-2010a). DP03, Selected Economic Characteristics, American Community Survey Selected Population Tables, Nassau County Hispanics, 2006-2010. Retrieved from http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_10_SF4_DP03&prodType=table.

U.S. Census Bureau. (2006-2010b). DP03, Selected Economic Characteristics, American Community Survey Selected Population Tables, Nassau County, 2006-2010. Retrieved from http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_10_5YR_DP03&prodType=table.

U.S. Census Bureau. (2006-2010c). DP02, Selected Social Characteristics in the United States, American Community Survey 5-Year Estimates, Nassau County, NY, 2006-2010. Retrieved from http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_10_SF4_DP02&prodType=table.

U.S. Department of Health and Human Services. (n.d.). Healthy People 2020, Disparities. Retrieved from http://healthypeople.gov/2020/about/disparitiesAbout.aspx.

Table 1: Community Health Assessment Tasks/Activities Completed by Week of Semester

Week	In Class	Homework
1	Introduce CHA and Class Project	Identify all ASD Service Providers in Nassau County; make a list with contact information
2	Review CHA example; Training on U.S. Census Bureau data for describing population demographics	Use U.S. Census Bureau web site data to describe social and demographic characteristics of Latinos in Nassau County
3	Dr. Levine conducts training on ASDs, diagnosis, therapies and cultural and social context	NA
4	Discussion of developing CHA purpose and goals	Write a concise statement of goals and objectives for class CHA project, brainstorm possible questions to ask providers and parents
5	Training in: Complying with human subjects procedures; conducting semi-structured interviews; verbatim note-taking	NA
6-8	Other CHA topics covered in class unrelated to project; questions about interviews addressed; student experiences interviewing providers discussed	Conduct interviews with service providers; write up and submit interview notes within 24 hours of interview
9	Instruction on how to develop a code-book for qualitative interviews	Develop draft code-book
10	Instruction on refining code-books and coding interviews; instruction on reporting and interpreting qualitative data	Revise and finalize codebook; Code interviews
11	Other CHA topics discussed	Write up rough draft of findings
12	Oral and written feedback on rough drafts provided to students	Revise report
13	Final report due Oral presentations of final reports	
Note: this table is specific to the CHA project and does not include all topics covered during the semester.		