

STUDY OF ACCESS TO HEALTH CARE SERVICES IN THE SOUTHEAST HEIGHTS

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Abstract

Context Perceiving persistent difficulties in local residents' being able to readily access health care at neighborhood clinics and at the parent hospital (University of New Mexico Hospital) serving the Southeast Heights section of Albuquerque, a community-based agency requested an analysis of the process of access to determine points where the process might be improved.

Objective: Create a compendium of experiences illustrating where and how perceived barriers to care occurred and make these available to administrative authorities within the care system for review and possible action.

Design, Setting, and Participants: The study used qualitative methods. Persons within the target neighborhood who self-identified as having had difficulties accessing or engaging the system of care were invited to participate in focus groups designed to draw out description of their experience. Fifty-three participants engaged in a total of six focus groups, which were conducted in December 2004. Many were Spanish-speaking and most had low incomes. Many were immigrants, some with illegal status, others with legal status. Some had no source of payment for care; others had Medicaid, participated in UNM Care, a plan for low income residents of the county, or Medicare. A content analysis of the focus groups allowed for identification of common themes and the sorting of the information by clinical site and according to stage of the process of care: first contact, scheduling, front desk issues, clinical encounter, payment, and financial aid information.

Results: Difficulties were perceived repeatedly at each stage for each of the clinical sites. Illustrative examples are presented regarding timely scheduling of services, the process of triage, waiting times, the perceived quality of care, communications issues, the process of payment and follow-up. Many expressed concerns about how they were treated. The results were not notably different between those who spoke English or Spanish-only or those with a source of payment and those without.

Conclusions: While the study does not provide a quantitative assessment of the perceived problems, numerous and specific barriers to access and care as perceived by study participants are described, suggesting systemic underlying problems. This information may be of use in finding ways to better address the needs of low income people who depend on the services at these clinic facilities.

Introduction and Background

In August 2004, Leah Steimel, then Program Director of Community Health Partnership, approached the Institute for Public Health for assistance in analyzing the barriers to accessing clinical services offered by the UNM Hospital in the Southeast Heights neighborhoods of Albuquerque. Community Health Partnership is a community-based advocacy organization located in the Southeast Heights. The issue, she explained, was not to document whether there were problems or demonstrate their extent, but to understand for those who were having problems where the problems were occurring in the process of access to care. She observed that difficulties had persisted over time. Her premise was that the process of accessing care had many steps, starting with a person's perception that a clinic visit was needed and ending with an effective clinical encounter and that an analysis of steps in this sequence might uncover remediable problems that stood in the way of access. Ultimately, such analysis could identify how the process could be improved.

The Institute for Public Health has ongoing interest in finding community-based partners and in building relationships that could be helpful in providing educational settings and research opportunities. Assisting Community Health Partnership was an opportunity for such a relationship.

Limitations in resources precluded an observational analysis of system components. Modest funding from the McCune Foundation was available and allowed for a circumscribed qualitative study and analysis. The study would draw directly from the experiences of those who had had difficulties of access and service. Inferences about the nature of the problems might then be inferred. The limitations in the approach precluded any attempt to quantify the extent of the problem.

Celia Iriart, PhD developed and then implemented a study plan for bringing forward participants from the community and using focus groups to elicit information. The specific design drew on validated qualitative research methodologies. The study was reviewed and approved by the UNM School of Medicine Human Research Review Committee. The infrastructure for implementing the study would be created at the community level. To do this efficiently and with local credibility, Voices for Children, with active presence in the community, was invited and agreed to serve as fiscal intermediary in contracting for community participation in the project.

Focus groups were held in December 2004.

Objective and Methods of the Study

The study was conducted to identify and analyze health care access problems reported by people living in Southeast Heights area in Albuquerque, Zip Code 87108. The data were collected through focus groups. Participants were adults

self-identified as having health care service access problems during the previous 12 months at the UNM Southeast Heights Clinics (adult, youth, and children clinics) and/or at the UNM Hospital. Parents experienced these problems when trying to access the clinic and the hospital for their children's health problems. Using this qualitative method, we collected detailed information about their problems of access and their knowledge about financial assistance available at the UNM Hospital.

Six focus groups were conducted totaling 53 participants, 42 women and 11 men. Six participants were American citizens, the rest (47) were immigrants from Mexico, of which 10 were legal residents. Around 20 cases were patients with financial coverage of health care, notably children with Medicaid, but also adults with Medicaid, Medicare, and UNM Care.

The methodology was qualitative.² This approach solicits ideas and opinions of a limited number of target population representatives regarding a defined topic. Focus group methodology collects data in a manner that respects the culture, language, and literacy levels of various audiences, and has proven effective with ethnic minorities. Focus groups can be used to explore a range of sensitive topics that may be difficult to do using other methods, and about which respondents are usually reticent to talk. The use of focus groups has been adapted from the fields of business and marketing to the social sciences and medicine over the past decade. Focus group research operates on the premise that attitudes and perceptions are not developed in isolation but through interaction with others. Although reflective of the views of the individual members, focus groups often lead to a broader expression of ideas and concerns. The primary goal of this focus group research was to gain a depth of understanding about the research topics, rather than knowledge that can be generalized to a larger population or group.

Focus Group Procedures

Community Health Partnership (CHP), a non-profit organization that provides advocacy for people in this region of Albuquerque, was responsible for recruiting participants using a screening form in places frequented by residents of the Southeast Heights area of Albuquerque (churches, supermarkets, etc.). The recruiting process was more difficult than expected. People reported being afraid of reprisals, despite guaranteed confidentiality. Our expectation was to have 60 participants in the groups, but several participants chose not to participate after recruitment and confirmation.

Complimentary food was provided to all participants before the focus groups as an incentive for participation, along with childcare during the discussion. During

² For more information on the qualitative methodological approach used in this study, see: Bernard, H. *Social Research Methods. Qualitative and Quantitative Approaches*. Thousand Oaks: Sage Publications. 2000.

the meal, each participant was provided with two copies of a written consent form in English or Spanish depending upon their preferred language. The consent form was read to participants in both English and Spanish, and questions were solicited and answered. A bilingual team member was available to respond to questions, confusion, and concerns. Participants were assured that participation would not require disclosure of personal health information. Once all questions have been answered, participants signed and returned one copy of the consent form and kept a second copy for their personal records.

Two trained team members moderated each focus group discussion; both were fluent in Spanish and English. All discussions were audio taped and notes were taken during the sessions. Upon leaving, participants received a letter of appreciation and a \$15 gift card for their contribution to the study. The entire session for each focus group, including dinner or breakfast, orientation, group discussion and wrap-up, lasted about 2 hours.

Data Analysis

Qualitative data from the focus group discussions were analyzed by first listening to the audio taped sessions and reading the notes taken during the groups. Principal ideas were transcribed to become familiar with the range of responses and identify emergent themes with respect to the processes and stages pertaining to access to care. Review of the audiotapes and transcripts was conducted several times during the data analysis. Matrices of the range of responses in different analytical categories were constructed and reviewed to identify substantively meaningful themes and patterns within and across data segments. Findings from this analysis were interpreted and summarized.

Description of the Area where People were Recruited

Focus groups participants lived in the Zip Code 87108. As reported in the 2000 Census, Hispanics comprise 45.5 percent of the population. Thirty-two percent of those over 17 years old speak Spanish at home. The area is the second highest area in Albuquerque in percentages of foreign-born, non-citizens, unemployed, and persons living in poverty. The area shows low performance regarding health indicators. See Appendix A for additional detail.

Results: Information from the Focus Groups

Focus groups were conducted in December 2004. The results that follow summarize and itemize comments as made by participants. Since the nature of

the inquiry was to elicit and display the perceptions of the participants, no attempt here has been made to validate what was stated.

The results are organized as those that are common to all sites and those that are for each of the three sites:

1. Experiences Common for Southeast Heights Family Practice Clinic (SEHFPC), Young Children Health Clinic (YCHC), and UNM Hospital (UNMH)
2. Experiences Specific for SEHFPC
3. Experiences Specific for YCHC
4. Experiences Specific for UNMH

For each site the results address respectively the following components of access and encounter:

- General access problems
- First contact, phone and/or front desk
- Scheduling
- Clinical encounter
- Payment system
- Financial assistance information

1. Experiences Common for SEHFPC, YCHC, and UNMH

General access problems:

- Many respondents felt a lack of control when they entered the medical system, since they were totally dependent on clinic staff for information regarding programs and payment plans, and on physicians and nurses regarding medical treatment and cost of services. Patients mentioned that they felt powerless and there was a deliberate attempt to keep them uninformed. Patients gained this insight from going to clinics with and without outside advocates. The courtesy given and information shared was greatly improved when advocates accompanied the patients.
- Dental health services were difficult to obtain in spite of the fact that there was a dental facility next to the San Pablo clinic.
- In cases where children and adults decided to change health services to First Nations Clinic, they considered the attention there to be much better.
- Some people said their experiences at Presbyterian Hospital were much better than at UNMH, even though service there was potentially more expensive. The front desk people were warm and the physicians took time to explain illnesses and treatment options. At Presbyterian and Lovelace, emergency room (ER) they received treatment faster than at UNMH.

First contact, phone and front desk:

- Most of the administrative staff, nurses, and professionals did not have Spanish language skills or cultural and social sensitivity. Some personnel denied that they could speak Spanish after patients had already witnessed them speaking Spanish earlier. Interpreters were not available regularly.
- People who were Spanish speakers, uninsured, lacking a social security number, or who had difficulty paying their medical bills experienced lack of respect from clinic staff. Front desk staff repeatedly made rude and hurtful comments about financial and family situations of uninsured or poor patients. They interrogated people about possession of cars, homes in Mexico, income, etc.
- Lack of respect was not specific to Spanish-speakers. English speakers on the UNM Care Program expressed the same problems of invasive and discriminatory treatment, specifically that staff could be arrogant.
- Front desk personnel and nurses often performed a triage role, deciding whether the patient's medical condition was urgent or sufficiently serious to warrant immediate clinic or ER care, or whether the person could take care of the condition at home. In some instances, physicians later told patients that those front-desk decisions were wrong and had put the patient or family member at risk. Physicians would sometimes intervene with front desk personnel to ensure that sick patients received correct information or were seen that day for serious illness.

Scheduling:

- Participants reported that it was difficult to obtain appointments for routine health maintenance checkups. Physicians often worked in their clinic only one or two days a week, in which case, continuity was next to impossible. Once a patient was assigned to a physician, when that physician was busy or on vacation, it was difficult to obtain an appointment with another provider.

Clinical encounters:

- The consultation process took a long time -- hours just to be triaged, and then more time to be seen by the provider. Some participants reported waiting so long after triage that the clinics were closed before the provider could even see them.
- Participants expressed that they often could not determine whether their provider was an attending, resident, physician assistant, or nurse practitioner.
- Providers often didn't explain the health problem, treatment options, or test strategies to patients. They didn't provide basic health education (example: managing a child with diarrhea or fever at home). Preventive health information generally was not provided in the clinical encounter.
- Language barriers and lack of professional interpreters made consultations difficult.

Payment system:

- Uninsured patients had to pay \$50 prior to being seen at either clinic. In all settings, patients had to wait for the bill at home without having any idea about what the total charge might be. Participants claimed that the cost was expensive given the quality of consultation or length of visit.
- The bills were generally incomprehensible. It was difficult to interpret what services were being charged or covered from the bill.
- People felt frustrated because they did not know which documents or payments were required up-front for services, making it difficult to access financial assistance.
- People who didn't pay their bills were threatened with being reported to the credit bureau. This caused anxiety, especially among undocumented people who did not know if it could further compromise their immigration situation.

Financial aid information:

- Most of the people participating in the focus groups did not have any information about financial aid (33% hospital discount, 45% physician discount or UNM Care Program). Others commented that it was almost impossible to obtain correct and timely information. In the clinics, staff sent patients to the financial aid office at UNM Hospital even when they had an office located in the SE Heights Clinic. Some participants, including some with high school and university levels of education, mentioned that the paperwork was very complicated and discouraged the completion of the application process.

2. Specific Information about the SEHFPC

Front desk:

- Patients complained they received different answers to the same question, and that services such as family planning were denied to uninsured individuals, despite the fact that the clinic receives Title X funding.
- Participants characterized staff designated to help people apply for social assistance as racist and blaming immigrants for U.S. economic problems. Staff did not provide correct information much of the time. Some described receiving better information when accompanied by an advocate or case manager.

Scheduling:

- Booking an appointment by telephone was often difficult, and the answering machine instructions were hard to follow. People waited for up to 30 minutes for somebody to respond. Patients had to wait for up to a month to see a particular doctor, and appointments were sometimes cancelled without informing the patient until the person arrived at the clinic. Similarly, when the clinic referred an individual to the hospital for specialty care, the scheduling was often incorrect.
- If the patient went directly to the clinic without an appointment they had to wait three or four hours to know if a provider can see him or her. Normally

- only three or four people could receive same day appointments in this way. If there were more people, they returned another day, obtained an appointment for the future, or went to the ER for care.
- It was difficult for new patients to enter in the system. The clinic was closed to new patients except for pregnant women. Even so, participants in the focus groups said that it was difficult to obtain an appointment for prenatal care, especially if the person could not show an income, the income was low, or she didn't have insurance. When some women finally got an appointment in their fourth or fifth month of pregnancy, the provider asked why they waited so long to be seen, blaming the woman for being remiss in her health care. Even before the list was closed, there was an example of an Anglo woman on UNM Care (not pregnant) who tried for two years to obtain an appointment with a primary care physician at SE Heights FP Clinic. The personnel informed her that she was on a waiting list. She eventually decided to go to First Choice, despite the fact that it was farther from her home.
 - People with UNM Care felt that they received worse attention than people with private insurance. They waited longer to get appointments and waited longer to be seen in the clinic when they had an appointment.

Clinical encounters:

- Some pregnant patients didn't have specific providers assigned. Patients were not sure whether providers were physicians or not.
- A patient with advanced diabetes was denied a medical certification for years that would prove he was unable to work and needed to receive social security funds. Another physician in the same clinic saw the patient and asked why he was working in this condition. That physician immediately provided the certification.
- Patients who did not speak English found it difficult to understand the medical and procedural jargon used in the clinic.
- Many patients complained that the medical staff did not explain what they were doing or why certain tests are ordered, and that frequently they provided inadequate care. After waiting long hours to be seen, the medical consultation was often only 5 minutes in length, with the doctors doing little more than writing prescriptions. Participants related serious health care problems: lack of a correct diagnosis that compromised the health of patients for months, incorrect prescriptions, and mistakes reading test results, among others.
- A person with an injury to her hand received minimal care without being offered the tetanus vaccine (the nurse washed the wound superficially and provided a bandage). They asked that she return the next day. When another provider saw the patient, he said that the injury was infected and sent her to the ER.
- Participants in the focus groups reported serious medical errors in diagnoses. Example: two patients with stomach pain were sent home for months saying they did not have anything wrong. Each finally got an ultrasound and was diagnosed with gallstones. For several months more,

the hospital refused to do the surgery saying that the cases were not urgent. (One had insurance and the other did not.) Eventually each went through the ER as an urgent case. In one case the gallbladder ruptured. In both cases, the Hospital providers criticized them and/or relatives for not acting fast enough.

- A pregnant woman tried to obtain care in the clinic with her regular physician for cramps she had experienced since the first months of her pregnancy. The front desk triaged her to the ER, where she was seen for the first time. They did an ultrasound, said that everything was fine, and didn't prescribe anything. Another time subsequently, she went to ER, they refused to see her because she went so frequently. Each time, she stayed for hours in the hospital without receiving any care, and finally stopped going. At some point she saw a different physician at the clinic (an attending) who prescribed some medication, the cramping stopped. Later, she delivered normally.
- A patient on Medicaid with asthma and diabetes was denied influenza vaccine. Later she developed pneumonia and needed to see a physician twice a week for two months, and believes not having the vaccine contributed.
- A participant visited the clinic several times because she had vaginal discharge with a bad odor. The clinic tested her for different infections but couldn't find a cause. At the time of the focus group, she was still worried and didn't feel secure with the care that she received at the clinic.

Payment system:

- Despite serious illnesses, patients who were unable to pay upfront for medical tests were denied access to these services.
- It was difficult to obtain referrals for people without insurance if they did not pay in advance. (Example: a woman with severe headache was to get an MRI, but clinic personnel said she had to pay in advance. She didn't have economic means to do so.)
- Information about billing was confusing for the focus group participants. Example: a pregnant woman went to the front desk with bills she had received. She was told earlier that she qualified for free assistance. The front desk person took the bills and threw them out, stating only that she didn't need to pay these bills. This patient received similar bills later and decided to throw them out as the clinic employee had done before.

Financial aid information:

- People in the focus group reported that recently the Hospital changed the staff person who was in charge of providing financial aid information. That person was described as warm, spoke Spanish, and was empathetic to patients' problems. Participants commented that the new person is rude, cannot speak Spanish, and is unwilling to help people.

3. Specific Information about the YCHC

Scheduling:

- Appointments were available on a same-day basis only to those people who called between 7:30 and 8:00 am. The telephone system was difficult to navigate. Callers were shunted into an answering machine waiting system so that by the time they talked to a real person, the day's appointments were already filled. The people who checked noticed that the English line was consistently answered before the Spanish line. The receptionists recommended that if the person calling thinks their kid needed urgent care, they should go directly to the ER.
- At the time of the focus group the clinic was not receiving new patients, just newborn babies.
- Spanish speakers felt discriminated against in both appointment booking and in receiving medical care.
- If a child had previously been to the clinic and assigned a particular physician, it was almost impossible for him/her to be seen by another physician if their usual doctor was not available.

Clinical encounters:

- Parents felt that uninsured children received less medical attention than children who had insurance.
- Even with an appointment, the wait for a physician could be up to six or seven hours. Many parents felt that physicians provided an inadequate amount of time and attention when they finally saw the children.
- Parents claimed that some physicians, especially those that were not the physician in charge of the patient, were not willing to check the records in the computer and ask the parents for information about diseases, medications, etc. In some cases, participants commented about serious mistakes which only parents who were deeply involved in the detailed care of their children could prevent (like prescribing wrong medicines, stopping medications, among others).
- Another medical error was made with a girl diagnosed as having a viral infection for four months. When the mother took the girl to Mexico, a physician there treated her for pneumonia with an antibiotic and "saved her life." He wrote a note for the physician in the clinic, but the physician continued denying it was pneumonia. Two other cases involved poor diagnoses regarding ear problems. Both children had hearing loss and are under complex and expensive treatments because they didn't receive early and correct diagnoses and treatment.

Payment system:

- The clinic charged the parents of uninsured children \$170 for three shots for each child, despite the fact that these vaccines were supposed to be freely provided to uninsured individuals through a program offered by the NM DOH (Vaccines for Children Program) in its office right next to the clinic. The front desk staff did not inform the parents about this option.

Several participants talked about the difficulty in obtaining vaccinations in the clinic for financial reasons, despite bringing notices from the school that the children would be dropped if they didn't get their vaccines.

4. Specific Information about UNMH

General access problems:

- Some of the participants, including Americans, used to complain at the administrative level for the problems that they had in trying to obtain care at the UNM Hospital, but nobody responded. They used the mechanisms they felt the hospital had designed. They felt this was not useful because the system seems created to protect the people inside the system not the patients.

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Interpreters:

- There was a lack of Spanish-speaking providers and interpreters throughout the hospital system, from the front desk to the ER and physicians, seriously affecting the capacity of the providers to understand health care needs of the patients and provide them adequate information.

Scheduling:

- Patients were informed that it could take months to get an appointment with a primary care physician at the hospital, regardless of how serious the case might be.

Clinical encounters:

- Patients with appointments were still forced to wait a long time before they could get into the examining room to see the doctor.

ER Front desk:

- ER patients were forced to wait for hours before being seen (8-9 hours were common experiences, but also several cases reported that they were waiting 24 or more hours in the ER). In some cases, these waits led to worsening injuries and fatalities. Some people left the ER after a whole day of waiting without any care. The explanation for such waits is always lack of beds. In other cases, relatives or friends with English skills were able to force the entry of the patients past the front desk and obtained needed care.
- Pregnant women going to the ER for delivery had to wait for hours to be seen. When a physician saw one patient, he asked why the front desk left her waiting when she was ready to deliver, noting that it could be dangerous for the baby.
- In another case, the baby died after the mother had waited two hours to get past the front desk. The mother had regular prenatal care, and the last visit showed a healthy fetus. When she arrived at 1:00 PM, the hospital didn't have interpreters in the ER, and she and her husband had a hard time trying to complete the forms and understand the situation. They

- never received an adequate explanation about why the baby died or the results of the autopsy.
- A person with high blood pressure was in the waiting room of the ER for hours until a relative decided to take her into the restricted area. When a physician finally saw her, he asked why she was waiting for so long when she could have been close to having a stroke.
 - Another person went to the ER with half her face swollen. She waited for hours. A medication was prescribed, apparently for allergic reaction. She returned to the ER again because her face became completely inflamed. Again she waited for hours and left the hospital without being seen. Her condition worsened and her relatives decided to bring her to First Choice. Again she waited for hours until a physician saw her in the waiting room and brought her immediately to be checked. He referred her back to UNMH ER where, despite having a referral from First Choice, she once again waited for hours before receiving care. They found that she had developed diabetes with high glucose.

Clinical encounters:

- The quality of medical care was uneven: several people reported being seen and tested by doctors at UNMH and told there was nothing wrong with them, despite having what turned out to be broken bones, diabetes, and coronary disease.
- A participant of the focus group who lost a finger in a work-related accident waited nine hours in the ER without receiving any pain treatment. When the specialist came, it was too late for the finger to be sewn back on. Another person entered with a deep cut on the hand and was left bleeding without any care for hours. This patient finally left and went to Lovelace where he received prompt attention.
- People related that while they might wait for hours, others seemed to be called more quickly even if they looked less serious. Participants believed that this occurred when people appeared to be of a higher social status.
- One person reported that she entered the ER after a serious car accident near Grants. She had an initial diagnosis of a broken arm and abdominal injuries couldn't be treated at Grants. At UNMH she had surgery for her abdominal problem and remained in the hospital for several days. UNMH took several X-rays of her arm, but she was discharged without any treatment for the arm. Nurses and others told her that the arm was fine. Several months afterwards, her arm remained symptomatic, so she consulted a private practitioner who informed her that the arm was broken and she would need to return to UNMH for treatment. She required surgery and physical therapy, but the hospital did not charge her for either procedure. Her initial surgery cost over \$22,000.
- It was difficult to get prescriptions filled correctly, especially for narcotics. One participant who was taking morphine had serious problems filling his prescriptions on time. He reported that there are always something missing like a signature or date and these scripts are only valid for 24 hours. This caused a lot of stress for the patient.

- A young adult with severe arthritis didn't receive treatment from UNMH because they didn't believe his diagnosis and didn't test him. The patient was in pain; his mobility worsened until he was almost bed-bound. He went to Presbyterian where he was tested and his arthritis confirmed. The patient was receiving treatment at SEHFPC at the time of the focus group. His health has improved, permitting him to work.
- Several people commented that they had problems getting blood tests done because nurses and techs were unable to take their blood correctly. Several people reported they had problems for weeks as a result of blood drawing, including some who suffered permanent injuries.

Payment system:

- In the ER, it was not uncommon for staff to request insurance information or upfront payment before treating a patient, and withholding care if their financial situation was questionable.
- The hospital sent a bill for services that the patient didn't receive. This happened to a person who registered to receive care, but, after waiting for hours, decided to leave the ER without seeing a doctor.
- Some participants never received a bill, but at some point received a call from a collection agency.
- People that needed surgery were required to pay 50% of the surgery in advance. It was the same situation at the Cancer Center. An American woman explained that she had cancer and was treated at the Cancer Center. Each visit, she needed to pay part of the cost of the treatments in advance. After several surgeries and treatments, she was unable to continue controlling her disease because she couldn't afford the payments. She declared bankruptcy because her medical debt. She is afraid to return because of the debt, believing that in cases with financial problems like hers, the Cancer Center would ask for the total payment in advance.
- People received bills for thousand dollars. Some people received huge bills (e.g. \$ 3,000) from the ER for short doctor visits, having their vital signs checked and being provided Tylenol without receiving explanation of diagnosis or treatment.

Financial aid:

- When people made financial agreements to pay their bills, they would not receive written confirmation of the agreement. Participants said that the agreements were arbitrarily changed by the hospital.
- Charges and copays were high for hospital procedures, and patients complained that they had not been fully informed of discounts (33% for hospital procedures and 45% for medical consultation) and payment options.

Discussion

Participants recruited into the focus groups were self-identified as having had problems with care received either at the UNM Hospital or one or both of the two UNMH operated clinics in the area. The problems, criticisms, and concerns that came up, therefore, may not reflect the general experience of patients, or even most patients. While Community Health Partnership, the agency that requested this study, expressed the view that it was commonplace for patients from the Southeast Heights to have difficulty with access and care, the present study does not permit quantification of the scope of the problems.

No attempt was made to verify the experiences recounted by the participants. The stories were strictly from the individuals' own points of view. It is entirely possible that circumstances of some could be readily explained with additional information beyond the participant's awareness or memory.

Focus group observers felt confident that the participants were sincere in their efforts to provide information. Participants said they felt comfortable with the researchers and openly shared their experiences. Most appeared motivated by the desire to see the hospital system improve. The sessions were sometimes emotional in character with some participants crying, for example, when they recounted experiences of trying to access health care services or of receiving calls from collection agencies or staff from the hospital or clinics demanding payment.

The usefulness of the information lies in its being an account of the perceived experiences of the participants. Furthermore, the examples in this report were selected because they reflect recurring themes offered in the focus groups. The content analysis determined that the stories drew upon common experiences.

The study looked at where in the sequence of steps surrounding the clinical encounter problems of access were particularly evident. The results indicate that problems were repeatedly perceived at nearly every step at each of the sites: difficulties scheduling and receiving timely appointments, rude or brusque encounters by receptionists or during intake, triage errors, extraordinary waiting times in the clinic or ER, the lack of confidence in some instances in the quality of the clinical encounter itself, insufficient or ineffective education at discharge, demands for pre-payments that were impossible to meet, billings that were incomprehensible, and intimidating collection practices.

There were many cross-cutting issues: inadequate or absent interpreters, instructions that were not clear or misunderstood, baffling regulations and administrative procedures, breakdowns in communication, difficulties achieving continuity of care, and a lack of preventive services. Of particular concern were the perceptions of not being respected and of one's word not being trusted. A recurrent implication was that many clinic staff had other priorities that subordinated concern for the patient's wellbeing.

Having to enter and negotiate a complicated and generally unfamiliar health care system can be daunting and frightening – the more so if one is ill or injured or concerned about a sick child. The focus group participants probably spoke for many of the least empowered to overcome obstacles of a large system. A majority were Hispanic, many lacking skills with English, most with low incomes, and many without an identifiable source of payment for health care. Many were immigrants - some illegal, others legal. Most felt an urgent need of services. For many, there were no alternative choices of where else to go. To some extent, most felt powerless.

Whether or not the experiences related in the focus groups are typical, it is not possible to conclude why the problems identified are occurring, whether selected examples of rare or idiosyncratic behaviors of staff, or due perhaps to insufficient training of staff, insufficient or ineffective quality control, overstressed and overwhelmed capacity, de-prioritization and/or under-financing of overwhelmed ambulatory care services, or other stresses within the system that diminish capacity to offer traditional concern and or fulfill a mission of providing care for the sick.⁴

Policies that selectively generate financial barriers to access or segregate according to ability to pay, for example, for persons who are classified as “self-pay,” may nurture tolerance of disrespect.

The experiences of the participants in the focus groups demonstrate a disconnection between these patients’ needs and expectations for service and their perception of the hospital’s lack of willingness and/or capacity to provide it. Participants’ frustration is derived in part by the lack of perception of how or whether the hospital manages accountability for the quality of its services.

Perceptions of institutional and/or personal discrimination were implied and at times directly voiced during the sessions. It should be noted, however, that English speakers, Americans by birth, and persons with insurance were well represented among the participants. These people voiced many of the same concerns and described many of the same problems that the others did.

The authors hope the incidents recounted in this report will not be dismissed as the inevitable discontent felt at the far end of some distribution curve or spectrum of perceived experience. This study offers a take-off point for more detailed analysis of problems identified in the focus groups. Such analysis might begin with a determination of whether a reported incident reflects a situation that departs from institutional intention or values, and proceed to evaluation of the prevalence and magnitude of the problem, and careful assessment of whether

⁴ From its vision statement for 2010, “The UNMHSC ambulatory care delivery system is designed to meet patient needs through geographically dispersed sites and timely access to health care providers, (and is) the safety net provider for the residents of Bernalillo County and, either directory or through its partners, provides high quality primary care services that are accessible to the communities it serves.”

the experience was idiosyncratic or the outgrowth of underlying, systemic issues. A model for such analysis is in the traditional “morbidity and mortality” conference (for example in maternal mortality), where the recognition and study of untoward outcomes become the starting point for understanding the issues and improving services and practices for the benefit of others in the future.

Appendix A: Health and Social Indicators for Zip Code Area 87108

The following summarize the health and social indicators compiled for Zip Code area 87108:⁵

- In 2000, the population under 15 years old was 20.1 percent of the population in the area, while 13.3 percent was over 65 years old.
- Hispanics comprise 45.5 percent of the population. 32.4 percent of the population over 17 years old spoke Spanish at home. The Zip Code 87108 is the second highest area in Albuquerque in relation to population of foreign-born, non-citizens, in 2000, with 15.0 percent.
- The percentage of unemployed in the labor force represented 9.0 percent, second highest in Albuquerque.
- 49.0 percent of the people in this Zip Code in 1999 lived under the poverty line (165 percent of Federal Poverty Level), the second highest rate in Albuquerque.
- The percentage of families with children under 18 years was 36.5 percent. The poverty level among families with children under 18 years old in 1999 was 17.9 percent, again the second highest in Albuquerque. Median household income in 1998 was \$16,858, third lowest in Albuquerque.
- The area is fourth for the population 25 years or older who had not completed high school in 2000, and has the second highest percentage of children ages 5 thru 17 not enrolled in school (7.5 percent).
- Census 2000 showed that 64.5 percent of the population pays rent for living space.
- In relation to the indicator 5 years (1996-2000) to mothers 15-19 years old show that 630 births were registered in this area, the third highest teenage birth rate in Albuquerque (NMDOH Vital Records and Health Statistics).
- The mean annual infant death rate in 1996-2000 was 7.87 per 1,000, fifth highest in Albuquerque (NMDOH Vital Records and Health Statistics).
- The percent of kids with asthma (2000), as well as the asthma hospital rates per 10,000 persons (1996-2000) were the highest in Albuquerque, 3.6 percent and 41.3 per 10,000, respectively (NMDOH, Children's Medical Services, Children's Chronic Conditions Registry, Jan. 2001).
- Hepatitis B cases between 1998 to 2002 were second highest in Albuquerque (11.7 percent but the total number is low, 22 cases) (NMDOH, Public Health Division, Office of Epidemiology)

⁵ Khanlian, S and Scharmen, T. *Albuquerque and Bernalillo County Zip Code Maps. Health and Social Indicators. Report 2004.* Office of Community Assessment, Planning and Evaluation. District 1, Public Health Division, New Mexico Department of Health. Most of the data come from U.S. Census 2000, however some data is from other sources and may reflect other time periods.

- The mean annual incidence of HIV and AIDS cases between 1981 and 2002 was 21.36 per 100,000, third highest in Albuquerque (NMDOH, Public Health Division, Office of Epidemiology).
- In 2000, 68.0 percent of population under 19 years and 14.9 percent of the population over 19 were enrolled in Medicaid, second and third highest in Albuquerque, respectively.
- The rate for 1996 to 2000 of driving under the influence of alcohol was 17.8 per 1000 population and the illegal drug-related police response rate was 20.1 per 1000. These rates represented the second highest rates in Albuquerque for these indicators. The rate of prostitution-related police responses was 11.84 per 1000, the highest in Albuquerque (Albuquerque Police Department).