

Report on the  
Findings and Recommendations of

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PROJECT ACCESS:  
A Medical, Legal and  
Case Management Collaboration

June 2000 – December 2004

PROJECT ACCESS

Health & Disability Advocates  
Mount Sinai Children's Hospital  
Sinai Urban Health Institute  
University of Chicago Children's Hospital

March 2005

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A Medical, Legal and  
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PROJECT ACCESS, an innovative medical, legal and case management collaboration, designed with the goal of increasing social supports and services for medically fragile infants and their families, was implemented and carefully evaluated in Chicago between June 2000 and December 2004. The families who participated in Project Access were primarily low-income, socially disadvantaged residents of Chicago's south and west sides. Their infants – all born very low birth-weight (VLBW) or with serious medical complications – started life in the Neonatal Intensive Care Unit (NICU) of one of the two participating hospitals, usually for several weeks or months, placing an inordinate amount of stress on already vulnerable families. Project Access's cross-disciplinary pool of professionals – doctors, lawyers, social workers, and nurse case managers – worked with families from the time of the infant's NICU stay for up to a year following hospital discharge and attempted to alleviate some of the families' stress by offering a range of benefits and services to assist with infant and family care.

In the comprehensive report that follows, the Project Access team presents its design and intervention methodology, explaining why and how the program services were established and implemented. Detailed results from the NICU Infant Outcomes Study (NIOS), the randomized, controlled study of Project Access services, are included in this report and reveal several areas where the program amassed a great deal of new information about participants' needs, and also dramatically improved support systems to meet those needs. In addition to the wealth of information garnered from NIOS, the report discusses some Project Access client success stories, as well as several broader advocacy victories, where systemic barriers to family support were effectively reduced or removed.

Of course, our job is to share not only programmatic successes but also to elucidate areas where our efforts were not as effective. Thus, the report discloses areas where we learned the limits of the Project Access intervention and includes our analysis of these limits, as well as a discussion of possible areas for future exploration. After disseminating valuable information learned through the program and research study, we offer ideas for future program development and underscore the need for funding of new programs targeted toward families with medically complex infants.

Highlights of some of Project Access program findings and outcomes that are discussed in detail include the following:

- NIOS, the study of Project Access, has generated a comprehensive new data set about the first year of life for high-risk infants and their families, covering topics as diverse as: infant health and development, family demographics, life stressors, psychosocial and health profiles of caregivers, family housing, and use of social service programs. This previously unreported information proves essential to understanding the impact of Project Access and will be invaluable in the design of future programs targeting this population.
- The demographic data and psychosocial profiles reveal that in addition to being poor and under-educated, the mothers of high-risk infants face more stressful events and have less support than similarly impoverished mothers of healthy newborn infants.
- Many families of high-risk infants live in unsafe or substandard housing and need to move frequently, which demonstrably affects families' ability to comply with recommended medical care.

- Providing participating families with legal advocacy and case management support during the first year of their infants' lives leads to improved and expedited access to a range of important public benefits such as Supplemental Security Income (SSI) and Temporary Assistance for Needy Families (TANF). In fact, legal advocacy resulted in receipt of benefits in 143 of the 150 interventions made by the Project Access lawyer or 95% of the total cases.
- Development of relationships between hospital staff and state and federal administrative agency personnel enhances access to public benefits for families, and reduces workloads for doctors, case managers, and administrative agency case-handlers. Establishing agency “outposts” at hospitals further expedites and simplifies receipt of benefits.
- Many families of high-risk infants do not fully utilize Early Intervention (EI) services that offer important developmental therapies; Project Access case management and legal services were not successful in increasing participation rates in the EI program.
- The Project Access service model reaches across professional boundaries and integrates social factors into medical care, enabling its physicians to provide more socially and culturally competent health care, which is especially important in treating extremely high-risk infants.
- Creating a “Medical Home” enables the families of high-risk infants to access a range of professional services, all within the medical care setting, and prevents them from having to navigate a complex maze of disparate systems.
- The Project Access service delivery system improves upon the traditional legal services model by allowing attorneys to work proactively, helping families to address problems as they arise and before they reach crisis levels.

LOW SOCIO-ECONOMIC STATUS has been repeatedly demonstrated to have negative effects on the health of children, including higher incidences of mortality and disability, as well as unmet health needs.<sup>1,2,3,4</sup> The combination of low socio-economic status and medical complications at birth puts children at an increased risk for long-term health and developmental problems.

In the Spring of 2000, a group of public-interest attorneys, working in collaboration with social workers, nurses, pediatricians and neonatologists from Mount Sinai Children's Hospital (MS) and the University of Chicago Children's Hospital (UC), hypothesized that providing intensive case management and legal services to low income families of infants born prematurely and/or with special health care needs would help combat the barriers to obtaining medical care, as well as vital social support and developmental services.<sup>†</sup> This group developed "Project Access," an intervention designed to provide families of very low birthweight and/or medically complex infants with case management and legal services for a full year following the infant's discharge from the Neonatal Intensive Care Unit (NICU). With help from epidemiologists at the Sinai Urban Health Institute, the team also designed and implemented a research study, entitled NICU Infant Outcomes Study: a randomized-controlled study of Project Access services (NIOS).

Project Access began providing case management and legal services to eligible NICU families during the summer of 2000. After piloting the program for just over a year, the research team began implementing the program's research component in March 2002. Families were enrolled to participate in the research study and data collection began. Service delivery and data collection continued

at each participating institution until December 2004 when the program officially ended. At the conclusion of the program both the service delivery and data collection results were compiled.

### A. BACKGROUND: THE MEDICAL AND SOCIAL RISKS OF VERY LOW BIRTHWEIGHT INFANTS

Before looking at the specific details of Project Access, it is important to understand the rationale behind the program's development. A quick description of some of the challenges facing low birthweight infants and their families will provide the context necessary to understand both the program's design and its results.

Infants admitted to the NICU often have complex, chronic medical conditions which place them at higher risk of post-discharge mortality, childhood morbidity from acute and chronic illness, and long-term developmental and educational deficits. As a result, any minor lapse in care can lead to major health complications.

To further compound their complex medical needs, these children are also frequently born into socio-economically disadvantaged families. This combination of medical risk and socio-economic disadvantage poses substantial threats to families who are often in an already unstable situation. Their lack of financial resources and inadequate social and emotional support often leaves families unable to meet their infants' basic needs, let alone follow a complex set of post-discharge medical and developmental treatments and therapies.

Many families experience a range of barriers that prevent them from adhering to recommended care and services prescribed by the hospital staff. Some

<sup>†</sup> A third hospital, Illinois Masonic Medical Center, located on the north side of Chicago, also participated in the pilot phase of the Project Access intervention during the period from June 2000 – December 2001. However, when Illinois Masonic Medical Center became part of the Advocate Healthcare network in early 2002, significant reductions in the hospital's NICU patient population made continuation of the intervention and initiation of the NIOS study at that site impracticable. Thus, Illinois Masonic Medical Center did not participate in any phase of the NIOS research

of these barriers include: transportation problems to and from the hospital, lack of income to purchase supplies and prescriptions, insufficient education about proper neonatal care, unstable housing, and time constraints resulting from their need to care for other children or go to work. As noted above, failure to follow prescribed care, whatever the reason, can lead to major health consequences for the medically complex child.

### 1. THE VERY LOW BIRTHWEIGHT INFANT

Perhaps the greatest challenges facing these infants and their families are the risks associated with the infants' tenuous medical situations caused by their prematurity. The average weight of a newborn infant is 3400 grams (7 lbs. 8 oz.).<sup>5</sup> Infants born weighing less than 2500 grams (5 lbs. 8 oz.) are considered low birthweight and those born weighing less than 1500 grams (3 lbs 5 oz.) are considered very low birthweight (VLBW). These classifications are useful because decreasing birthweight often corresponds to increasing mortality (death) and morbidity (illnesses) for the infant.

From 1980 to 2002, the incidence of VLBW infants has increased from 1.2% to 1.5% of live births in the United States. In 2002, 58,544 infants, or 1.5%

of live births, were VLBW in the United States.<sup>6</sup> Major risk factors for very low birthweight include: multiple births, preterm delivery, smoking, inadequate maternal nutrition, maternal age extremes and short inter-pregnancy interval. Although black infants comprise 15% of live births in the United States, they account for 31% of babies with birth weights less than 1500 grams. The same is true in Chicago. Table I.1 shows the racial/ethnic breakdown of VLBW infants compared to other infants born in Chicago. Again, black infants account

TABLE I.1. THE RACIAL/ETHNIC BREAKDOWN OF VERY LOW BIRTHWEIGHT INFANTS COMPARED TO OTHER INFANTS, CHICAGO, 1996-1998\*

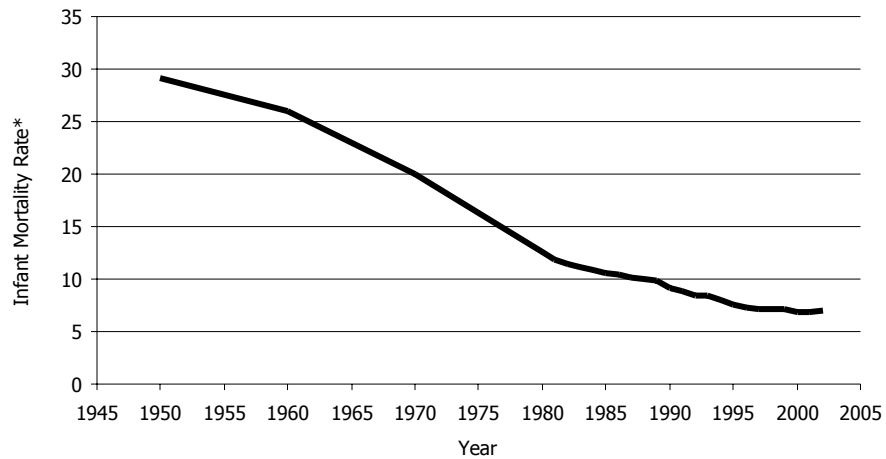
	VLBW	Other	Total
Black	66%	41%	42%
Hispanic	19%	34%	34%
White	13%	21%	21%
Other	2%	4%	4%

Source: Illinois Vital Statistics

\* Births are categorized by the race/ethnicity of mother

for a little less than half of the births in Chicago (42%), but they account for a disproportionate two-thirds (66%) of the VLBW births.<sup>7</sup>

FIGURE I.1.  
INFANT  
MORTALITY RATE  
IN THE UNITED  
STATES 1950 TO  
2000



Source: National Center for Health Statistics, National Vital Statistics System

\* per 1000 live births

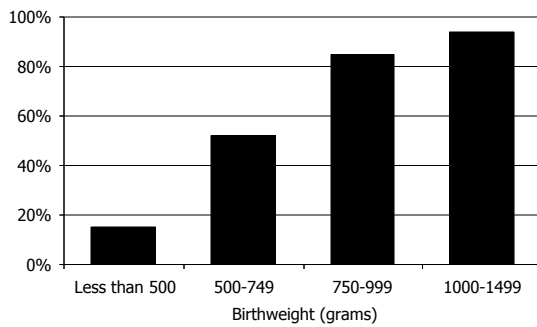


FIGURE I.2.  
PERCENT OF  
INFANTS WHO LIVE  
TO ONE YEAR OF  
AGE BY THEIR  
BIRTHWEIGHT IN THE  
UNITED STATES,  
2001

Source: National Center for Health Statistics, National Vital Statistics System

As medical technologies have advanced, more premature infants are able to survive. Specifically, Level III NICUs, like those at Mount Sinai Children’s Hospital and the University of Chicago Children’s Hospital, now routinely provide the resources and technology necessary to help VLBW infants survive. These advances have led to dramatic decreases in infant mortality in the United States. As Figure I.1 shows, overall mortality has decreased 76% since 1950 (from 29 infant deaths per 1000 live births in 1950 to 7 per 1000 in 2000).<sup>8</sup> Survivability, as shown in Figure I.2, also correlates well with birthweight (15% for birth weights <500 grams, 52% for birth weights of 500-749 grams, 85% for birth weights 750-999 grams, and 94% for birth weights of 1000-1499 grams).<sup>9</sup>

Not surprisingly, this dramatic decrease in infant mortality rates has led to increased costs in the medical care of premature infants. The medical cost for the initial care required by all newborn infants in the United States is approximately \$10.2 billion dollars. Of that \$10.2 billion, about 57% of it is spent on the initial medical care of low birthweight infants. This means that more than half of the total cost associated with caring for all newborn infants is spent on just 8% of all newborns.<sup>10</sup> A good illustration of this is the hospital cost for an infant’s NICU stay. The smallest premature infant may generate up to \$1 million in medical costs

during her NICU hospitalization.<sup>11</sup> All of this demonstrates that society has made a significant investment in the successful NICU treatment and hospitalization of these infants.

## 2. CHALLENGES FACING FAMILIES OF VLBW INFANTS

The increasing number of low birthweight infants born each year has led to an increased level of need among the families of these high-risk infants. As a result, it is critical that there are resources available to meet their needs. These necessary additional resources in turn create an increased burden on society. Unfortunately, despite the substantial resources allocated toward the NICU care of these infants, there are significantly fewer resources invested in their long-term follow-up care.

Not surprisingly, with these increased survival rates also come challenges for caregivers trying to meet the needs of medically complex infants. For example, low birthweight infants are forty times more likely to die during their first month of life than non-low birthweight infants. Those low birthweight infants that do survive are three times more likely than normal weight infants to suffer chronic physical and learning disabilities. They are also five times more likely to be re-hospitalized than healthy newborn infants.<sup>12</sup>

Unfortunately, sick infants often lead to sick children. In fact, VLBW infants are at increased risk of a host of long-term medical problems, such as:

- Chronic respiratory problems;
- Vision and hearing deficits;
- Growth and nutritional deficiencies;
- Neurologic impairments; and
- Developmental problems.

These infants' increased medical complexity combined with their families' social disadvantage leaves them at extremely high-risk for a whole host of problems. Not surprisingly, social factors exert a profound influence on the health of children. In fact, the child's risk for medical and developmental complications does not end with their successful hospital treatment and discharge. Their low socio-economic status leaves them at significant risk for ongoing complications once they return home. For example, a high percentage of families, especially those with limited education and income, have considerable difficulty obtaining the full range of medical and developmental services prescribed for their high-risk infants. This can lead to medical complications that negatively affect the health and development of these infants. It also frequently results in the unnecessary use of expensive medical resources for remedial treatments during unscheduled emergency room visits and hospitalizations.

Early childhood is a critical time period in brain development. The impact of the care and services received by infants in early childhood can be seen well into their early school years. Not surprisingly, low birthweight infants require follow-up with multiple doctors after their discharge from the NICU, with a typical VLBW infant seeing four different specialists who each require separate appointments.<sup>15</sup>

Families who do not fully follow their child's prescribed medical care plan often do so because they lack the essential

resources necessary to be compliant. For instance, low maternal education, limited access to appropriate healthcare, limited income and unstable housing may all contribute to a family's inability to meet their child's ongoing medical needs. Hospitals generally do not assume the responsibility to help families obtain the essential logistical resources that would enable them to comply with their child's medical service plans. In fact, reimbursement restrictions have recently led to shortened hospital stays for newborns and their mothers in every birth category, making failure to comply with medical service plans a problem in both normal and high-risk deliveries. In addition, hospital staff in the NICU often do not have the time, training, or personnel available to help families effectively overcome their multiple logistical barriers to obtaining follow-up care. This, combined with the fact that mothers of NICU infants tend to be younger, less educated, and have fewer resources than other new mothers leaves these infants at high-risk for a host of long-term medical and developmental problems.<sup>14</sup>

#### B. KEY ELEMENTS OF PROJECT ACCESS

Project Access, a novel medical, legal and case management collaboration, combined the expertise of staff from the University of Chicago Children's Hospital (UC) and Mount Sinai Children's Hospital (MS), each representing a different geographic portion of the city's diverse population; Health & Disability Advocates, a non-profit legal advocacy organization; and the Sinai Urban Health Institute, a public health research organization. The program was designed to improve both access to and the convenience of services available to families of high-risk infants. Its design recognized the combined risks associated with both medical complications and socio-economic disadvantage. By working with families of high-risk infants throughout the infants' first year of life, it also targeted a particularly critical

period in their growth and development. To address these families' needs, the project developed a proactive approach to service delivery. This innovative model helped families address issues before they reached crisis levels, thereby improving overall family functioning.

Several key elements were critical to the success of the Project Access service delivery model:

1. Project Access provided its families with intensive case management services to address their combined medical and socio-economic needs.
2. It also provided legal services on-site in both the hospitals' NICU and outpatient follow-up pediatric high-risk clinics. Because the project recognized the importance of convenience and access to services, the program offered both its case management and legal services components on-site in the medical care setting.
3. The project was set up as an interdisciplinary approach to

service delivery. This holistic model combined the services of social workers, attorneys, hospital administrators, physicians, nurses and other healthcare professionals.

4. Finally, the project was designed to help families learn about and access a broad range of social support services and developmental therapies to meet the needs of both the infants and their families.

Through these key elements the Project Access model provided coordinated and intensive medical, case management and legal services to families of high-risk infants—from the birth of the infant through his or her first year—to help overcome barriers to accessing healthcare and other critical social support and developmental services. This four-year demonstration project at two Chicago area hospitals was designed to improve the support systems for families of infants newly discharged from neonatal intensive care units. Figure I.3 is a visual representation of the Project Access model.

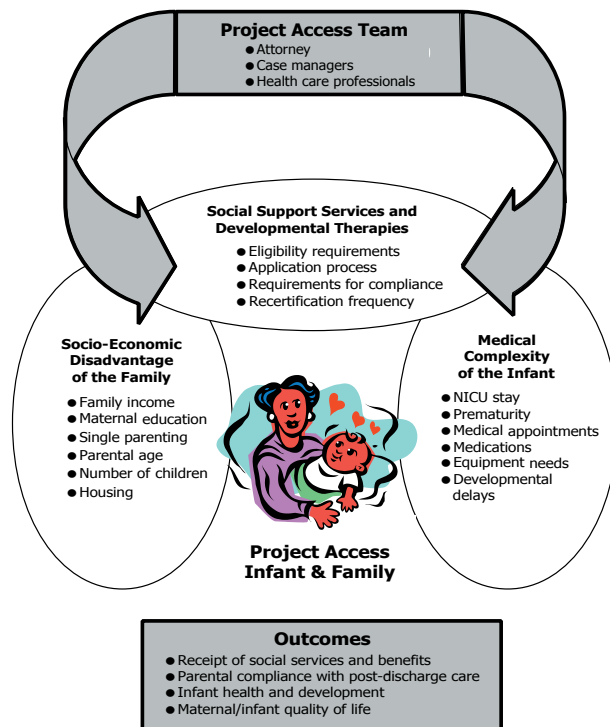


FIGURE I.3.  
PROJECT ACCESS  
MODEL

## II. Description of the Intervention

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PROJECT ACCESS was unique among other service models in that it was both multidisciplinary and holistic. For those reasons, the intervention had many components designed to address the varying needs of participating families. To fully understand the service delivery model and its research results it is important to have a clear understanding of the intervention design and function. One of the most important components of the intervention was its multidisciplinary, team approach. Case managers, physicians, nurses, hospital administrators, lawyers and researchers worked together with the families to share information, resources, and professional insights and to identify family goals and meet family needs. Appendix A contains a list of key Project Access team members and their roles within the intervention.

### A. THE PROJECT ACCESS CASE MANAGEMENT MODEL

One of the most important components of the Project Access intervention was its case management model. Both of the project's participating hospitals, University of Chicago Children's Hospital (UC) and Mount Sinai Children's Hospital (MS), had a full-time Project Access case manager onsite who provided services to participating families.

Case management services offered valuable resources, support and information to these families at what was often a very unstable time in their lives. In addition, because mothers of NICU infants are often younger, less educated, and have fewer available resources than other new mothers, they tend to have more difficulty following crucial follow-up care instructions. Some of the logistical barriers that often prevent parents from successfully completing prescribed treatments or accessing

services necessary to care for their infants include:

- Lack of transportation to the hospital and outpatient appointments;
- Insufficient income to purchase supplies and prescriptions;
- Low levels of maternal education;
- Insufficient information about proper neonatal care;
- Difficulty making time for multiple follow-up appointments due to employment;
- Lack of appropriate, affordable child care for other children; and
- Lack of stable housing.

While some hospitals will help families overcome these barriers while the infant is an inpatient, such assistance from hospital personnel usually ceases once the infant is discharged. With the infant at home, the mother is expected to cope on her own while adjusting to her new responsibility to care for her special needs infant. Even in circumstances where NICU personnel assume some of the responsibility for assisting families post-discharge, they typically do not have the time, training, or resources available to help families overcome their multiple logistical barriers and successfully provide their child with the necessary level of care and services.

In response to the obvious need within this population and the apparent lack of existing resources, Project Access designed a case management model to meet participants' ongoing need for a connection to the essential logistical supports that they have traditionally had difficulty accessing. Project Access case managers were trained to help families identify and access a range of benefits and services that would be necessary for them to successfully follow medical and developmental follow-up care regimens. The Project Access case management model focused not only on issues relating



to infant health, but also issues affecting family well-being such as: stable housing, education, transportation, employment, income, and child care. Families received intensive case management services beginning while the infant was in the NICU and continuing through the infant's first year of life, at each regularly scheduled outpatient pediatric appointment.

#### 1. PROJECT ACCESS CASE MANAGER ACTIVITIES

To accomplish the project's goal of connecting families to essential benefits and services, the case manager conducted all of the following activities with participating families:

- *Outreach* – case managers provided information to NICU patients and medical providers about the services available through Project Access;
- *Screening* – each NICU patient was assessed by the case managers to determine their eligibility for participation in Project Access;
- *Consenting Families* – those families who were determined to be eligible through the screening process were approached by case managers who reviewed the project's available services and participation requirements; consent was obtained from families interested in participating in the program's research study;
- *Assessment* – case managers met with all Project Access families while their infant was in the NICU to assess the families' need for benefits, supports and services;
- *Service Plan Development* – case managers, families and other relevant providers worked together to develop an Individualized Family Service Plan to meet the infant and family's ongoing needs;
- *Coordination of Care* – case managers also monitored and assisted in infant discharge planning, ordering

medical equipment, scheduling follow-up appointments and securing transportation to those follow-up appointments;

- *Benefits Counseling, Linkage and Enrollment* – appropriate benefit and service applications and referrals were completed with families to ensure that they made the necessary connections to social services and supports;
- *Care Monitoring* – post-discharge, case managers continued to check in with families on a regular basis to assess progress in obtaining necessary benefits and services;
- *Supportive Counseling* – because of the challenges associated with caring for a special needs child, case managers provided emotional support to all project families both during NICU hospitalization and follow-up care;
- *Reassessment* – to ensure that the program continued to meet families' ongoing needs, case managers continually identified new needs, concerns, and issues, and revised their service plan as necessary; and
- *Disengagement* – as families reached the end of Project Access services, case managers worked with them to plan for the future and their infants' long-term medical and developmental needs.

#### 2. AREAS OF PROJECT ACCESS SERVICE DELIVERY

Because of the project's holistic approach to service delivery, case managers provided assistance in accessing a comprehensive range of programs and services to Project Access families. In working with these programs, case managers took on numerous responsibilities including: educating families on available benefits and services; using their connections with agency personnel to make appropriate referrals; offering application advice and referral; and helping with appeals in situations where applications are denied. Some of the target areas of

the project's case management included:

- *Income Support Programs:* including Supplemental Security Income, Social Security Disability Insurance, unemployment insurance, and Temporary Assistance for Needy Families;
- *Health Insurance:* including comprehensive coverage from Medicaid, State Children's Health Insurance Programs, and private insurance programs, or supplementary coverage from the Division of Specialized Care for Children;
- *Developmental/Educational programs:* such as therapeutic programs like Early Intervention, Title V Programs, Individuals with Disabilities Education Act (IDEA), and special education needs;
- *Food and Nutrition Programs:* like the WIC and food stamp programs;
- *Housing Needs:* such as locating safe, affordable and accessible housing, securing homeless prevention funding, making appropriate referrals, and preventing evictions;
- *Transportation Needs:* including assistance in locating, scheduling and paying for secure transportation to medical appointments, Early Intervention services, and other treatment services that are part of the infant's medical care plan;
- *Immigration:* such as providing appropriate legal advice and referrals on immigration issues impacting Project Access newborns and their families;
- *Domestic Violence:* including assessing families needs for support and making appropriate referrals when necessary;
- *Childcare and Respite:* helping families connect with appropriate providers and locate payment assistance; and
- *Other Disability Issues:* including problems accessing and retaining necessary services that may be harder to secure due to a child's disability.

### 3. TRAITS/CHARACTERISTICS/SKILLS OF PROJECT ACCESS CASE MANAGERS

In providing all of the services described above, the case manager's role was to work on the ground level assisting families of NICU infants during their hospital stay and for one year following discharge. At the start of the program the case managers received extensive information and training on the range of social services and public benefits that impact NICU families. Throughout the project the case managers received ongoing training and supervision from the legal services team, as well as their in-hospital teams which included other members of the Social Work Department or Nurse Case Management Team.

The case managers identified the following skills and traits as essential to their work with families:

- Good communication skills;
- Flexibility;
- Practicality;
- Objectivity;
- Problem solving skills;
- Assertiveness;
- Ability to build rapport with different types/personalities;
- Organizational skills; and
- Listening skills.

### 4. PROJECT OPERATION AT EACH HOSPITAL SITE

After describing the Project Access case management services and the case managers' responsibilities, it is important to point out that there were several institutional differences that had a significant impact on the project's functioning. While the project was structured the same way at both hospital sites, over the last few years it became apparent that differences in hospital size and structure contributed to significant differences in how the project operated at each hospital. Several key institutional differences are worth further discussion.

- *Hospital Resources:* One of the main differences between the two participating hospitals was the hospitals' available resources. The University of Chicago Children's Hospital is a large institution with ties to a prominent university with a national reputation. The hospital has access to significant monetary resources and has a large NICU, with 53 beds serving more than 850 infants a year. Mount Sinai Children's Hospital on the contrary is a much smaller institution with very limited monetary resources. Their NICU is substantially smaller with 35 beds that serve just over 400 infants a year.
- *Hospital Staff:* The staff size and make-up at each institution also looks very different.

*Inpatient Staff:* At the University of Chicago Hospital, families in the NICU had contact with a large number of support staff including: 2 social workers, 2 case managers, physical therapists, a speech and swallow therapist, developmental therapist, nutritionist and the Project Access case manager. At Mount Sinai, the only support staff families had contact with in the NICU was the Project Access case manager. There was a hospital social worker who covered the NICU, but referrals were made to her only when social issues arose. She was not available for general advice and referrals requested by NICU families.

*Outpatient Staff:* Once the infant was discharged and returned to the hospital's outpatient clinic for follow-up care, other staffing issues were apparent. In addition to the child's pediatrician, families at the University of Chicago immediately had contact with the clinic social worker, nurse educator, physical therapist, developmental therapist, speech and swallow therapist, nutritionist, and of course, the Project Access case manager. At Mount Sinai,

families had contact with their child's pediatrician and the Project Access case manager. There was limited developmental screening done by physical and occupational therapists. All other services required referral to providers outside of the clinic.

- *Case Managers' Office Location:* Interestingly enough, the location of the case managers' offices at the two institutions impacted the way services were provided to project families. At the University of Chicago the case manager's office was located in a different building from the hospital NICU. At Mount Sinai on the other hand, the case manager's office was right inside the NICU.
- *Case Managers' Education and Training:* The case managers at each institution had different educational and training backgrounds. The University of Chicago case manager was a nurse and the Mount Sinai case manager was a social worker. Not surprisingly, this impacted the way they approached their work with project families.

The institutional differences described above each had a profound impact on the way the project operated at the two hospital sites. For instance, because of hospital differences families were enrolled into the study at different times at each site. At the University of Chicago, it was often unclear where infants would go to receive their pediatric follow-up care. As a result, enrollment typically did not occur until just prior to the infant's discharge from the NICU. Several factors made it difficult to determine where the infant would receive his or her follow-up care. First, because the hospital's clinic did not accept all types of insurance, many families with private insurance were not able to return to the hospital's clinic for their child's follow-up care. In addition, the size and reputation of the University of Chicago also caused the hospital to draw patients from a much larger geographic area. As a result, some infants who were hospitalized in the NICU

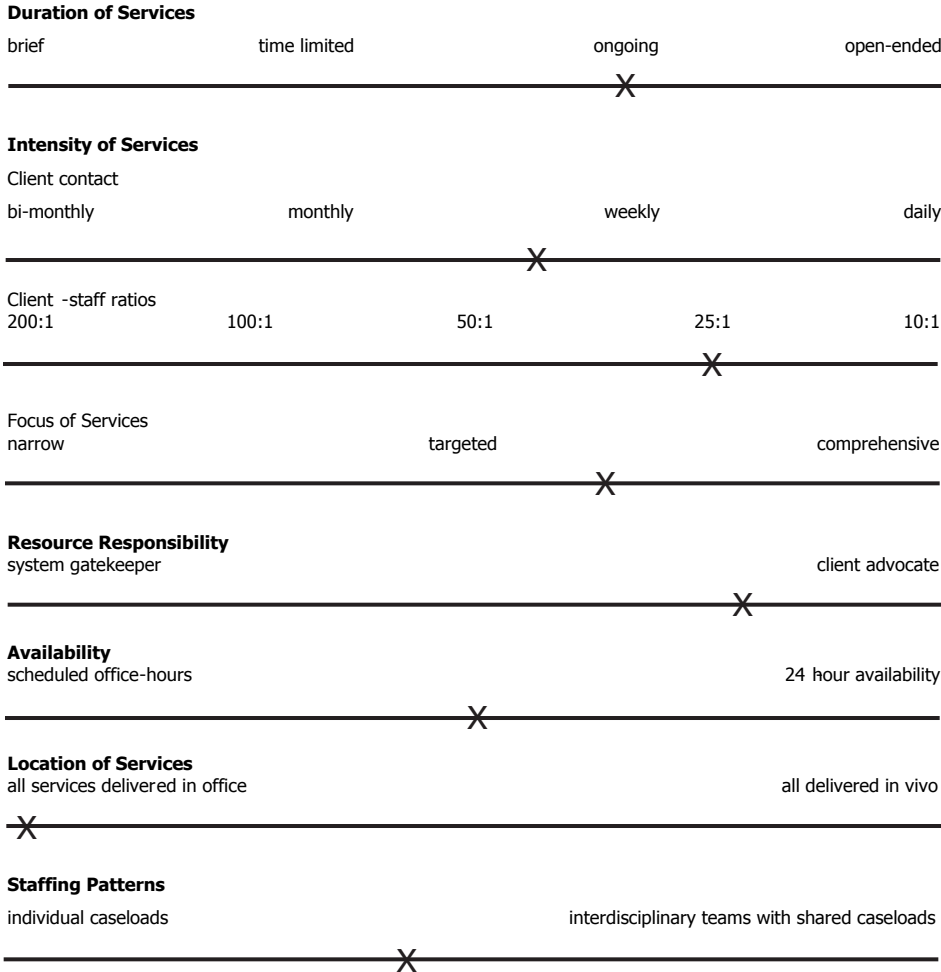
were actually hospitalized a significant distance from their home and would return to a local pediatrician for care post-discharge. At Mount Sinai on the other hand, enrollment into the study occurred much closer to the infant's birth because a much larger percentage of infants born at Mount Sinai will return to the outpatient follow-up clinic for care.

Sinai however, enrollment generally happened much earlier and as a result, a significant amount of relationship building occurred in the NICU. This made the transition from the NICU to the outpatient clinic much smoother because the case manager and attorney already knew the families' situations and could often get an earlier start in addressing some of their ongoing issues.

Because of these differences in the timing of enrollment, relationship building between the case manager and project families occurred at different times at the two institutions. The University of Chicago families were not enrolled into the study until quite close to their hospital discharge and consequently, relationship building occurred primarily in the hospital's outpatient clinic. At Mount

Another factor with a definite impact on the case managers' contact with the project families was the case manager's office location. As described above, at the University of Chicago, the case manager's office was located in an entirely different building from the hospital's NICU. At Mount Sinai, the case manager's office was right inside the

FIGURE II.1. CONTINUUM OF VARIABLES FOR CASE MANAGEMENT SERVICES



NICU. This made it much easier for the Mount Sinai case manager to meet with families in the NICU, especially since families often visit sporadically and at odd hours. The University of Chicago case manager often had more difficulty connecting with families while they were visiting their infants in the NICU simply because she was not always present in the NICU when they might arrive.

Finally, the background and training of the case managers definitely impacted the way they interacted with and provided services to participating families. Not surprisingly, the University of Chicago case manager who was a nurse interacted with families differently than the Mount Sinai case manager who was a social worker. As a result, the University of Chicago case manager provided a more immediate and direct link to the hospital's medical providers and offered patients more specific information about their infants' diagnoses, prognoses, medications and treatment plans. In contrast, the Mount Sinai case manager who was a social worker provided more supportive counseling and direct advocacy to families at her institution. All of these differences are reflected in varying degrees within the project's results.

## 5. PROJECT ACCESS CASE MANAGEMENT VS. OTHER CASE MANAGEMENT MODELS

After considering the tasks and skills of Project Access case managers, we mapped their roles and placed them in a continuum of variables for case management services (Figure II.1).

### B. PROJECT ACCESS LEGAL SERVICES

#### 1. OVERVIEW OF STAFF ATTORNEY'S ROLE

The Project Access staff attorney worked closely with the medical and case management teams to ensure that participating families received a range of essential logistical supports and benefits. The staff attorney, who was a trained lawyer and social worker (JD/MSW),

spent one day per week at each hospital and follow-up clinic site, meeting with Project Access participants and other team members. In this capacity, she provided direct legal services to clients. She also provided back-up support and coaching to case managers. On days she was not onsite at the hospitals or clinics, the staff attorney had regular contact with clients and case managers through phone conversations and email, and she regularly reviewed all case files.

The Project Access staff attorney also met frequently with the Project Access director to review caseloads and strategize about case handling. The attorney and director held quarterly case reviews to discuss each family's service plan. During this review they considered the steps that had been taken to meet the family's goals, the problems and barriers encountered along the way, and the strategies for handling problems in the future.

Along with the Project Access director, the staff attorney was also responsible for identifying systemic legal problems that have affected clients and for developing strategies to address these problems. This often happened throughout the course of their regular review meetings as patterns emerged from the staff attorney's work with participating families. When systemic problems were identified, the Project Access legal team developed strategies to address these problems and often used their contacts with state and federal agencies to work toward solutions.

The Project Access staff attorney's responsibilities thus included:

- Meeting with Project Access families on site at University of Chicago and Mount Sinai to assess their legal needs;
- Educating Project Access families on their rights and responsibilities within the benefit and service programs they utilized;
- Providing legal advice, counseling and representation to Project Access families on a range of civil legal issues;

- Coordinating legal services with medical providers, to ensure that accurate and timely medical records and reports accompanied client benefits applications and appeals;
- Providing benefits training to Project Access Case Managers;
- Serving as a resource on public benefits and social services to members of the Project Access medical team and to the larger community of hospital healthcare providers;
- Providing back-up coaching and support to Case Managers as they handled routine Project Access benefits issues; and
- Conducting advocacy with state and federal agencies to advance clients' rights individually and systemically.

## 2. LEGAL SERVICES OFFERED

The Project Access staff attorney offered participating families assistance with a wide variety of civil legal issues. When accessing public benefit and social service programs, families were educated on the relevant programs available to them. Each family was offered LEGAL COUNSELING through which the staff attorney provided information to the family about their rights and responsibilities under various social support programs. The staff attorney also offered information on how to apply for benefits, retain eligibility and appeal unfavorable determinations.

Families were then assisted in accessing and completing the application process for any of the benefits and services that they might be eligible for. Throughout their participation in the programs, the staff attorney also ensured that they remained eligible for benefits and complied with the programs' necessary requirements. When families encountered problems during the application process or lost their benefits after being found eligible, the staff attorney stepped in.

In many cases, the Staff Attorney also provided LEGAL ADVOCACY on behalf of participating families. When providing legal advocacy, the attorney contacted local, state or federal agencies by phone, letter or through administrative or regulatory procedures, to obtain a favorable result for her client. This included appealing unfavorable findings and determinations and representing clients in agency administrative proceedings or court hearings.

Throughout her work with participating families, the Project Access staff attorney provided ongoing legal assistance with a range of issues including things like:

- *Income Support Programs:* such as Supplemental Security Income, Social Security Disability Insurance, Unemployment insurance, and Temporary Assistance for Needy Families;
- *Health Insurance:* including comprehensive coverage from Medicaid, State Children's Health Insurance Programs, or private insurance programs; and supplementary coverage through the Division of Specialized Care for Children;
- *Developmental/Educational Programs:* like Early Intervention programs that provide therapeutic services to children aged 0 – 3, connecting with Title V Programs, IDEA and special education needs;
- *Food and Nutrition Programs:* including the WIC and Food Stamp programs;
- *Housing Needs:* such as locating safe, affordable and accessible housing, securing homeless prevention funding, making appropriate referrals, and preventing evictions;
- *Transportation Needs:* including assistance in locating, scheduling and paying for secure transportation to medical appointments, Early Intervention services, and other treatment services that are part of the infant's medical care plan;

- *Immigration*: such as providing appropriate legal advice and referrals on immigration issues impacting Project Access newborns and their families;
- *Domestic Violence*: including assessing families needs for support and making appropriate referrals when necessary;
- *Childcare and Respite*: helping families connect with appropriate providers and locate payment assistance; and
- *Other Disability Issues*: including any problems accessing and retaining necessary services.

As described above, the Project Access legal services model was unique in that it offered families access to legal advice and information before a crisis occurred. As a result, families received information early, so they knew how to avoid problems such as: losing benefits, evictions, or utility shut-offs. As such, the model was designed to be proactive and readily accessible, two features that distinguish it from most traditional legal services programs.

#### C. PROJECT ACCESS CASE EXAMPLE

To better illustrate how Project Access functioned for participating families, a case example is provided below. The narrative on the following page describes a typical Project Access case from Mount Sinai Hospital.

#### D. BENEFITS OF THE COLLABORATIVE MODEL

The Project Access case managers and staff attorney, whose roles are described in detail above, worked closely with the inpatient neonatology staff and with the pediatricians who followed infants after discharge. Project Access did not alter the usual standard of medical care offered to participating families; however, medical providers frequently reported that they appreciated having case management and legal resources available to assist their patients, and that they learned a great

deal about support programs available to help them. Not surprisingly, several advantages emerged from Project Access's emphasis on teamwork and collaboration.

First, the ongoing connection between attorneys and health care providers led to cross-discipline information sharing. This improved the ability of the medical, legal and case management professionals to advocate for their clients and better assist them in accessing programs and services. The model also led to ongoing educational opportunities. For attorneys, this provided the rare chance to learn about and function within the medical model. Likewise, for medical professionals, this model helped them to learn about the benefits that their patients are entitled to and the barriers they encounter in accessing those benefits. The collaborative team approach to service provision brought professionals from a range of disciplines together, helping them to work as a team in problem solving on behalf of their patients and clients. This also allowed the program to function as a proactive service delivery model, specifically targeted at addressing problems before they reach crisis levels rather than reacting to pre-existing situations. All in all, the increased communication and collaboration facilitated by the Project Access service delivery model generally led to better legal representation by the attorneys and improved patient care by case managers, doctors and other health care providers.

## Nina's Story

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On January 9, 2002, Nina was born at Mount Sinai Hospital. She was extremely premature at birth, born at just 26 weeks and weighing only 835 grams or 1.8 pounds. Shortly after birth, the doctors diagnosed her with several medical conditions including: PDA (patent ductus arteriosus), a common heart problem in premature infants; stage two ROP (retinopathy of prematurity) or abnormal eye development; and RDS (respiratory distress syndrome), the result of lungs that were not fully developed. In addition, she was diagnosed with a condition called amniotic band syndrome, which led to several physical abnormalities on her extremities and left her without the use of both her left hand and foot.

Because of her complex medical situation, Nina will have to undergo multiple surgeries throughout her first few years of life to correct her heart problem and give her full use of both her left hand and foot. She is also likely to have significant developmental delays as a result of her small size at birth and her hand and foot problems. These ongoing medical needs require continuous supervision. As a result, since her discharge from the Neonatal Intensive Care Unit (NICU), Nina has been followed by five different specialists: a cardiologist; orthopedist; ophthalmologist; gastroenterologist; and a high-risk pediatrician.

Nina's mother is in her early twenties and has a three-year-old son. She is a high school graduate who, at the time of Nina's birth, was living with her mother, Nina's maternal grandmother, and several other relatives. When she brought the baby home from the hospital, the total household size grew to 8 people. With a small child at home, Nina's mother was not working and was unaware of her eligibility for public benefits. She was also receiving no support from Nina's father.

The case manager at Mount Sinai screened and consented this family shortly after the baby's birth. Once she determined their eligibility for Project Access services, she conducted a full needs assessment. The case manager identified several priorities for her work with the family including: building income, ensuring medical coverage, setting up necessary post-discharge therapies and ensuring an appropriate home environment for Nina.

Based upon Nina's very low birthweight, she immediately did a Supplemental Security Income (SSI) referral. With the Project Access streamlined SSI application process, a representative from the Social Security Administration came out to the hospital to take Nina's application so that her mother would not have to make a special trip to one of their local offices. The application, which would normally take three months to complete, was then processed and approved within three weeks. This was critical for Nina's mom who had no income because it enabled her to begin receiving benefits even before the baby came home from the hospital.

Because of Nina's extensive medical needs, the case manager also made sure that both mom and baby were receiving Medicaid at discharge. To ensure a smooth transition from the hospital to the outpatient clinic, the case manager coordinated the medical card application with the hospital's billing department so that she could give Nina's mother the case id number prior to her first visit to the pediatric high-risk follow-up clinic and ensure their ability to see the baby's pediatrician right away. She also brought the mother to the clinic prior to the baby's discharge to ensure that she knew where to go and what to expect during their first follow-up visit.

The case manager then made both a WIC referral and an Early Intervention referral. The Early Intervention (EI) referral prior to the baby's discharge from the hospital ensured that an assessment would be done shortly after discharge and that therapy services would be in place to help minimize Nina's developmental delay. Without an EI referral before discharge, it often takes several months for services to be in place. Because of the case manager's quick referral, Nina received an EI assessment within a few weeks of discharge and is now receiving both physical therapy and developmental therapy at home, several times a week. Once services were in place, the case manager acted as the liaison between the EI provider and Nina's mother to help ensure that the therapy services continued as intended.



As the date for discharge neared, the case manager made sure that Nina's mother would have the necessary supplies at home when the baby was ready for discharge. Through community resources, she was able to provide the family with a car seat, bassinet, crib and baby clothes. She also made sure that the mother received all the necessary hospital pre-discharge training so that she would feel comfortable caring for Nina's special needs. In addition, the case manager counseled Nina's mom throughout the NICU hospitalization. She facilitated communication between the NICU doctors, nurses and the family. She also addressed crises that arose such as a lack of both food and transportation to and from the hospital.

During Nina's stay in the NICU, the case manager began talking to her mother about their living situation. It became apparent that the small apartment where she was living with seven other people was going to be an added source of stress for Nina's mother once the baby came home. The case manager began working with the mother to secure homeless prevention funding for the family so that mother and baby could move into their own apartment. This program, administered by local non-profit organizations, provides first month's rent and security deposit directly to a new landlord. The case manager also worked with Nina's mom to find appropriate housing referrals to locate an affordable apartment. Within a few months of Nina's discharge from the hospital, she and her mother and brother moved into their own apartment.

Unfortunately, shortly after they moved in, the landlord began to demand additional rent from Nina's mom, even though she had already received a full first month's rent and security deposit through the homeless prevention funds. The Project Access attorney was able to collect sufficient documentation from the agencies providing the homeless prevention funding to document receipt of both the rent and security deposit and to demonstrate the terms of the new tenancy. The attorney then communicated with the landlord directly to verify the terms of the tenancy, establish that first month's rent had already been paid in full, and avoid any future confusion or conflict. Two months into the tenancy Nina's mother located a more affordable apartment that was available for immediate occupancy, but was unsure of how to legally terminate her existing tenancy. The staff attorney then began communicating with the landlord to help facilitate the move. She was able to help Nina's mom terminate her tenancy by providing proper written notice and thereby ensuring the return of her security deposit. The family was then able to move into the more affordable apartment.

Several months after the Project Access team began working with the family, the Department of Human Services (DHS) cut Nina, her brother and their mother off Medicaid. DHS claimed that her mother had not responded to their phone calls and letters and as a result, closed their medical cases. The attorney was then able to advocate with DHS to have the Medicaid case reinstated for Nina, her mother and her 3 year old brother without the family having to go through the traditional DHS appeal process. While she was working with DHS on the medical case, the attorney was also able to facilitate the completion of a food stamp application for the family and a public aid application for Nina's older brother.

The case manager then worked with Nina's mom to complete a Division of Specialized Care for Children application to help the family cover things like home adaptation costs and respite care, both of which are necessary for Nina as she continues to grow. She also worked with Nina's mother to secure daycare so that she could begin a part time job. They eventually found funding through the Division of Children and Family Services to pay Nina's maternal grandmother to provide part time daycare for Nina's older brother. This has also helped her mother manage the almost constant medical appointments and doctors' visits that Nina requires.

Through their extensive work with the Project Access case manager and attorney, Nina and her mother have successfully faced several challenges. They regularly attend all of Nina's follow-up medical appointments. She is growing and gaining weight appropriately and has already had the first in a series of surgeries that will be required to repair her physical abnormalities. The program has also helped her mother achieve more independence. Heading her own household has empowered her and has enabled her to begin problem solving on her own before things reach crisis level.

### III. Study Methodology

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#### A. STUDY DESIGN

The NICU Infant Outcomes Study (NIOS) was a randomized controlled trial of Project Access services at two Chicago hospitals: Mount Sinai Children's Hospital (MS) and University of Chicago Children's Hospital (UC). The objectives of the study were to determine whether providing Project Access services 1) increased the families' access to critical medical and welfare services and 2) improved outcomes for the high-risk infants and mothers. The study took place between March 2002 and December 2004. The Institutional Review Boards at both institutions approved the study initially and at successive annual reviews.

#### B. RECRUITMENT AND ENROLLMENT OF PARTICIPANTS

The target population consisted of medically high-risk infants and their families. Study participants were recruited from the Neonatal Intensive Care Units (NICU) at the two study sites: Mount Sinai and the University of Chicago. Criteria for eligibility included: a) medical eligibility – very low birthweight (VLBW,  $\leq 1,500$  grams at birth) or risk for an adverse neurodevelopmental outcome (e.g., birth asphyxia, seizures, intra-cranial hemorrhage, need for extracorporeal membrane oxygenation (ECMO), congenital and/or chromosomal abnormalities); b) financial eligibility – total family income less than 285% of the Federal Poverty Guidelines; c) family intention to bring the infant to the participating hospital's high-risk, outpatient follow-up clinic post-discharge from the NICU for follow-up care; and d) lack of DCFS involvement with the infant. Infants who died early in their NICU stay were excluded from the study.

All infants admitted to the NICU were screened for medical eligibility. Infants

meeting the medical criteria were further screened for annual household income, plans for follow-up care, DCFS involvement, etc. Families with infants who met the eligibility criteria were approached and invited to participate in the research study. After consenting to participate, the infants and their families were randomized to either the intervention group receiving Project Access services or the control group receiving the traditional services offered in the outpatient high-risk clinic on a 2:1 basis (i.e., 2 to the intervention group to 1 to the control group). The randomization scheme included stratification by the two sites and the two designated medical groups: 'very low birthweight' and 'at risk for adverse neurodevelopmental outcome'. In cases of multiple births (e.g., twins), the last born and/or last surviving infant was designated the index infant for enrollment/randomization and his/her siblings were assigned to the same study group as the index infant. Data on the non-index sibling is not included in the analysis.

An overall summary of the recruitment, enrollment and retention of NIOS families is presented in Figure III.1. Figures III.2 and III.3 present this information for each institution. Between March 2002 and August 2003, the duration of study recruitment, 1938 infants were screened for eligibility: 508 at Mount Sinai and 1430 at the University of Chicago. Only 202 (10%) of the infants screened were eligible for NIOS. The main reason for ineligibility was that the infant did not meet the medical criteria for the study (70%). Other reasons for ineligibility include: not intending to bring the infant to the hospital's follow-up clinic (14%), early death of the infant (3%), DCFS involvement with the family (1%), and other reasons (1%).

As can be seen from Figures III.2 and III.3, the proportion of infants who were

eligible varied substantially between the two institutions: 18% at Mount Sinai, 8% at University of Chicago. Note that at the University of Chicago 240 (17%) of the families who were otherwise medically eligible for the study did not intend to bring the infant to the hospital's follow-up clinic compared to 34 (7%) of families at Mount Sinai. This difference primarily reflects the difference in access to the hospital's high-risk, outpatient follow-up clinic. University of Chicago's clinic did not accept all types of health insurance; thus, many families with private insurance were not able to return to the hospital for follow-up care. In addition, the University of Chicago drew patients from a larger geographic area and families would return to a more local pediatrician for care post-NICU discharge.

Of the 202 infants eligible at the time of NICU discharge, 163 (81%) were successfully recruited for NIOS, while 20 (10%) declined to participate and 19 (9%) were not available for consent. Of the 163 consented infants, 10 were siblings to a last-born and/or last surviving infant who, as the index infant for the study, was the one enrolled; therefore, a total of 153 infants and their families were randomized into the NIOS study. Figure III.4 presents the randomization by hospital, stratified by the two designated medical groups. Of the 153 infants randomized, 103 were randomized into Project Access and 50 into the control group. During the course of the study (~18 months), 45 families were lost to the study. The flow of NIOS participants from enrollment through discharge is examined in detail in the Results section, below.

FIGURE III.1. SUMMARY OF THE RECRUITMENT, ENROLLMENT AND RETENTION OF NIOS FAMILIES

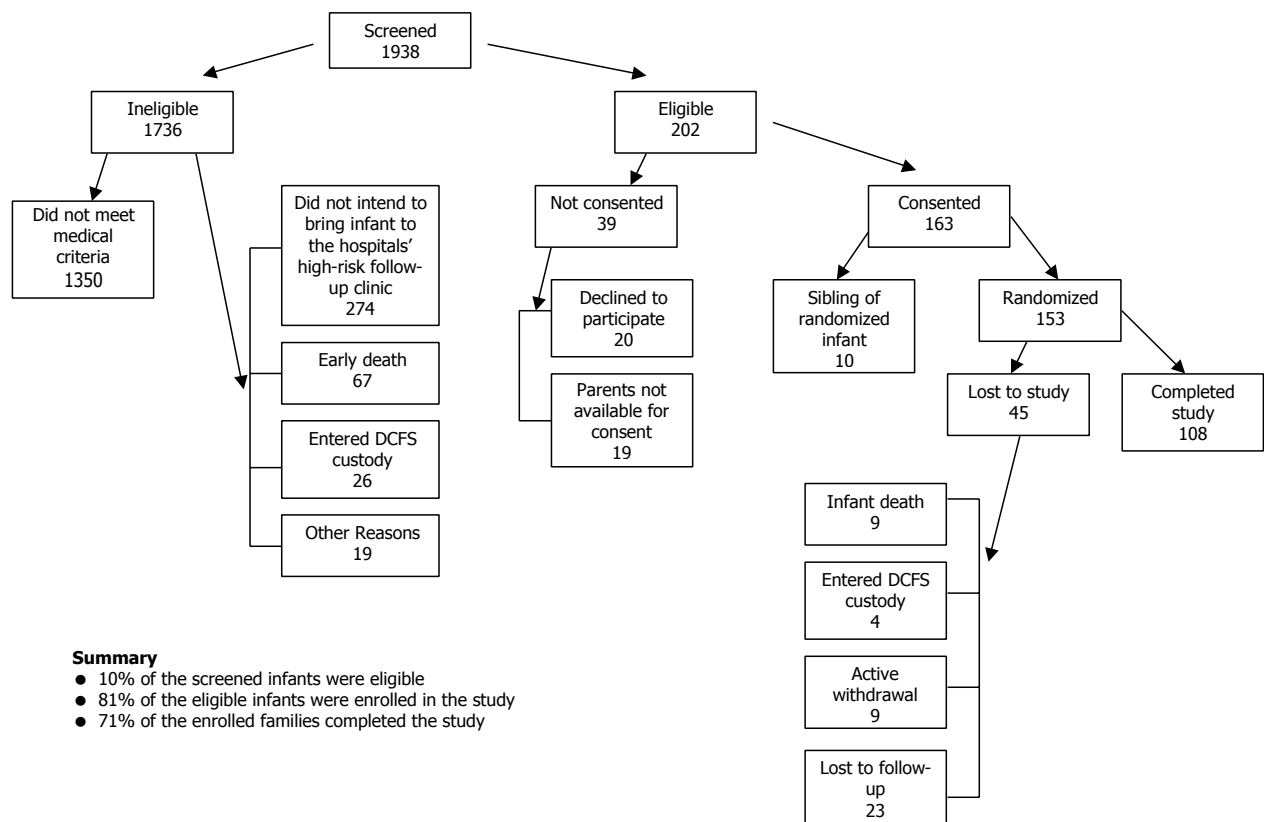


FIGURE III.2. SUMMARY ENROLLMENT AND RETENTION OF NIOS FAMILIES AT MOUNT SINAI

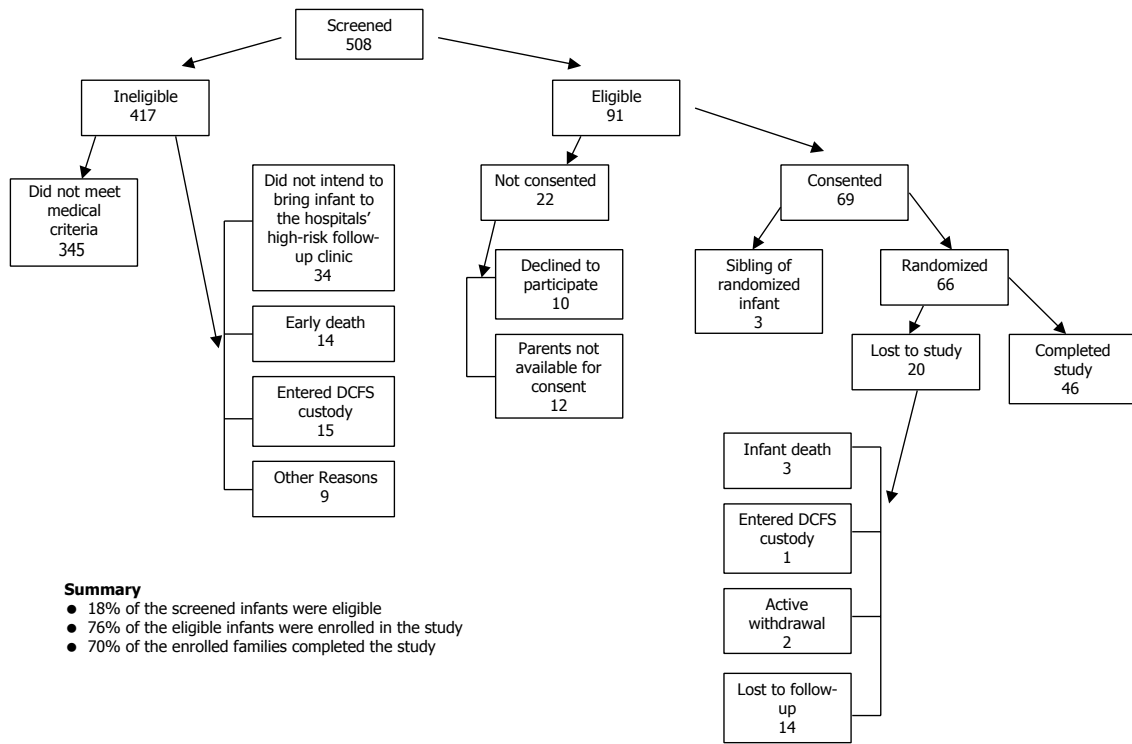


FIGURE III.3. SUMMARY ENROLLMENT AND RETENTION OF NIOS FAMILIES AT THE UNIVERSITY OF CHICAGO

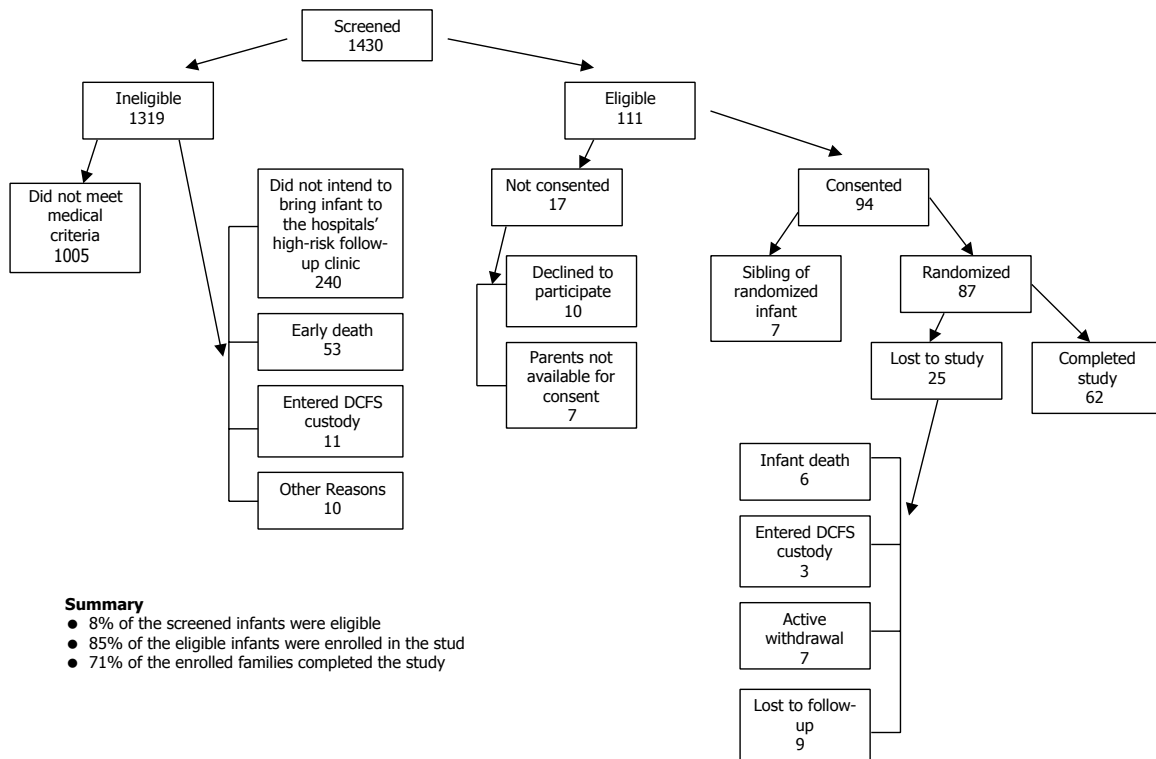
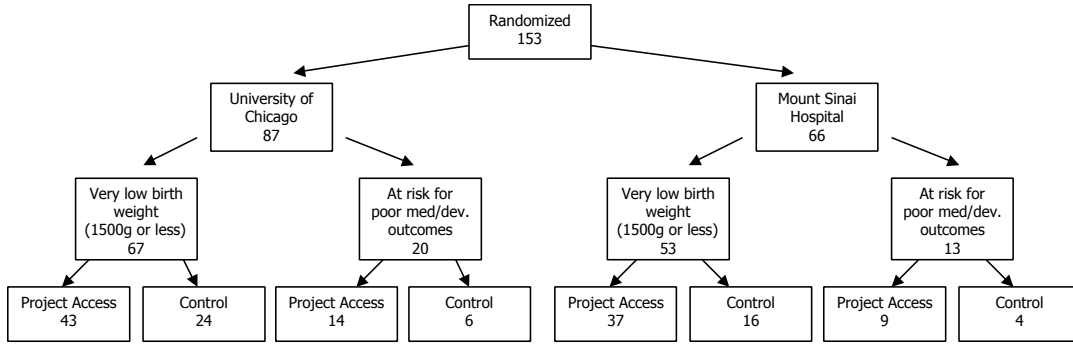


FIGURE III.4. RANDOMIZATION OF NIOS FAMILIES BY HOSPITAL OF ENROLLMENT



C. DATA COLLECTION

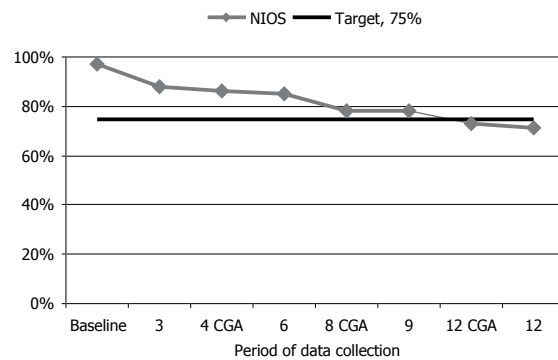
Near the time of NICU discharge (baseline) and every three months post-NICU discharge, as well as when the infants reached 4, 8, and 12 months corrected for gestational age (CGA), a trained NIOS research assistant administered a battery of standardized and research team designed instruments according to defined study protocol. Appendix B includes the timetable for data collection throughout the study.

The instruments selected were chosen in order to verify adequate randomization, define the study population, and assess several process and outcome measures. Each of the questionnaires is explained in detail as data from them are analyzed in the following Results section. The instruments included:

- Demographics questionnaire
- Housing module
- Social Services Survey
- Crisis in Family Systems (CRISYS)
- Social Support Survey (Modified from the MOS Social Support Survey)
- Multidimensional Health Locus of Control (MHLC)
- SF-36 Health Survey
- Provider Assessment of Compliance
- Unscheduled Use of Medical Facilities questionnaire
- Health Related Quality of Life (HRQOL)
- Ages and Stages Questionnaire (ASQ)
- Parenting Stress Index–Short Form (PSI-SF)
- Impact of Chronic Illness on a Family Survey

Over the course of the study, the NIOS research assistants conducted over 1000 interviews of families. Figure III.5 shows the rate of follow-up for each period of data collection (i.e., Baseline, 3 months post-NICU discharge, 4 months CGA, etc.) through the duration of the study. Of the 153 families who enrolled in NIOS, 108 (71%) completed the final interview at 12 months post-NICU discharge while 45 (29%) were lost to the study (Figure III.1). A more thorough discussion of those lost to study is provided in the Results section.

FIGURE III.5. RATE OF FOLLOW-UP FOR EACH PERIOD OF DATA COLLECTION



Source: NICU Infant Outcomes Study (NIOS)

In addition to the data collected by interview of the mother/caregiver, data was gathered from several supplementary sources including: infants’ and mothers’ medical records, hospitals’ computerized appointment systems, and Project Access case manager and staff attorney case notes. The data from the interviews and

the additional sources were all entered into the NIOS database.

#### D. OUTCOME MEASURES

To determine whether providing Project Access services 1) increases the families' access to critical medical and welfare services and 2) improves outcomes for the high-risk infants and mothers, four specific outcomes were defined:

1. Receipt of social services and benefits
2. Parental compliance with post-discharge care
3. Infant health and development
4. Maternal/infant quality of life

These measures are each explained as the data are analyzed in the report's Results section.

#### E. DATA ANALYSIS

Data for statistical analysis was exported into SAS statistical software, version 8.2 (SAS Institute, Inc., Cary, NC) for analysis. Statistical significance was determined by using chi-square tests or t-tests, as appropriate. Two-sided tests of hypothesis were used. For all statistical tests, a p-value of .05 or less was considered statistically significant.

### A. DEMOGRAPHIC DESCRIPTION OF HIGH-RISK INFANTS AND THEIR FAMILIES

One of the more significant ‘results’ of the NICU Infant Outcomes Study (NIOS) has been the wealth of information now available to researchers, physicians, policy makers, and program administrators regarding the first year of life of the high-risk infant and his/her family. The in-depth interviews of NIOS/Project Access families has provided information on topics as diverse as infant health and development, family demographics and general life stressors, psychosocial and health profiles of the mother/caregiver, the family’s housing situation and neighborhood context, and their knowledge and utilization of social service programs. To the best of our knowledge, no other data set as comprehensive has ever been assembled for this population. These data are being used to advocate for these families and impact systems change, both within the study institutions themselves and at state and national levels. Throughout this report, there are examples of how these data are being used on behalf of these families.

In the sections below, we focus on using the wealth of data to answer the question, “Who are NIOS/Project Access families?”

#### 1. INFANT HEALTH

As indicated in Figure III.1, of almost 2000 NICU admissions at the two hospitals over approximately 18 months, only 10% of the infants were eligible for the study. Most of those ineligible (78%) did not meet the medical criteria of either being very low birthweight or at risk for adverse neurological outcomes.

Table IV.1 presents a description of the infants’ health at the time of their enrollment in NIOS. As you can see, the distributions of the characteristics

across the Project Access and control groups were approximately equivalent, as determined by either chi-square tests or t-tests of statistical significance. Of the 5 variables for which data are presented in Table IV.1, none demonstrate statistical significance (i.e., none of the p-values are less than 0.05). However, one variable approaches statistical significance. The proportion of males in the control group was higher than in the Project Access group (72% vs. 57%,  $p=0.08$ ). Overall, the sample was 62% male, 78% very low birthweight, had an average length stay of 70 days in the NICU (i.e., a little over 2 months), and 65% had complex medical needs at the time of discharge (see the footnote in Table IV.1). Consistent with the flow charts presented in the Methodology section, more than half (57%) of the families came from University of Chicago.

Of the 153 infants enrolled, 119 or 78% were very low birthweight (birthweight  $\leq 1500$  grams, VLBW). The ‘VLBW group’ had a mean gestational age of 27 weeks (or 9 weeks premature) and an average birthweight of 977 grams. 15% were diagnosed with a grade III/IV intraventricular hemorrhage, periventricular leukomalacia (PVL), or moderate to severe ventriculomegaly; 40% were diagnosed with chronic lung disease; and 14% had retinopathy of prematurity requiring surgery. The average length of stay in the NICU for these infants was 78 days and 70% had complex needs at discharge. See Table IV.2 for a description of the infants’ health needs by primary medical criteria.

The mean gestational age and birthweight of the 22% in the ‘at risk for adverse neurological outcomes’ group was 37 weeks and 2911 grams respectively. 48% of these infants were born with major congenital anomalies; 21% with a high risk for poor neurological outcome

TABLE IV. 1. DESCRIPTION OF THE INFANTS' HEALTH AT THE TIME OF THEIR ENROLLMENT IN NIOS

Infant Health	Mount Sinai			University of Chicago			Both Sites			p-value*
	Proj Access n=46	Control n=20	Total n=66	Proj Access n=57	Control n=30	Total n=87	Proj Access n=103	Control n=50	Total n=153	
Gender										
Males	57%	65%	59%	58%	77%	64%	57%	72%	62%	0.08
Females	43%	35%	41%	42%	23%	36%	43%	28%	38%	
Birthweight										
Less than 1000 grams	48%	40%	45%	44%	33%	40%	46%	36%	42%	0.29
1000 - 1500 grams	33%	40%	35%	30%	47%	36%	31%	44%	35%	
More than 1500 grams	20%	20%	20%	26%	20%	24%	23%	20%	22%	
Primary medical criteria for enrollment										
Very low birthweight	80%	80%	80%	75%	80%	77%	78%	80%	78%	0.74
At risk for adverse neurological outcomes	20%	20%	20%	25%	20%	23%	22%	20%	22%	
Average length of NICU stay	64 days	53 days	61 days	76 days	78 days	76 days	70 days	68 days	70 days	0.74
Complex needs at discharge <sup>†,^</sup>										
Yes	56%	37%	50%	75%	80%	77%	66%	63%	65%	0.71
No	44%	63%	50%	25%	20%	23%	34%	37%	35%	

Source: NICU Infant Outcome Study (NIOS)

\* The results are considered statistically significant if the probability of the result (the "p-value") is less than 5% or 0.05. The p-values shown are for statistical comparisons between Project Access and Control groups. Statistical comparisons between each hospital and between groups at each hospital are not shown.

† Complex needs at discharge include one or more of the following: 1) the need for home equipment such as oxygen and/or home apnea monitoring, 2) the requirement of nasogastric/gastric tube feedings, or 3) 3 or more subspecialty follow-up appointments.

^ 3 infants are missing this information: 2 infants were transferred to other hospitals and 1 infant died as a NICU inpatient (n=150: 101 Project Access, 49 Control).



TABLE IV. 2. DESCRIPTION OF THE INFANTS' HEALTH BY PRIMARY MEDICAL CRITERIA

Infant Health	Very low birthweight	At risk for poor med/dev. outcomes	Total
	n=120	n=33	n=153
Gestational age at birth	27 weeks	37 weeks	29 weeks
Average weight at birth	977 grams	2911 grams	1394 grams
Grade III/IV IVH, PVL, or severe-to-moderate ventriculomegaly	15%	15%	15%
Chronic lung disease*	40%	-	-
Retinopathy of prematurity requiring surgery^	14%	-	-
Diagnosis			
ECMO	-	9%	-
History of neonatal seizures	-	21%	-
Major congenital anomalies	-	48%	-
Risk for poor neurologic outcome	-	21%	-
Average length of NICU stay	78 days	38 days	70 days
Complex needs at discharge#+	70%	47%	65%

Source: NICU Infant Outcome Study (NIOS)

\* 1 infant is missing this information (n=119)

^ 2 infants are missing this information (n=118)

# 3 infants are missing this information: 2 were transferred to other hospitals and 1 infant died as a NICU inpatient (n=150: 118 'Very low birthweight', 32 'At risk for poor med/dev. outcomes').

+ Complex needs at discharge include one or more of the following: 1) the need for home equipment such as oxygen and/or home apnea monitoring, 2) the requirement of nasogastric/gastric tube feedings, or 3) 3 or more subspecialty follow-up appointments.

secondary to their primary diagnosis (i.e., hydrocephalus, neurofibromatosis, etc.); 21% with a diagnosis of seizures; and 9% required extracorporeal membrane oxygenation (ECMO). These infants required a shorter stay in the NICU and fewer had complex needs at discharge, 38 days and 47% respectively.

## 2. MATERNAL DEMOGRAPHICS

Table IV.3 presents a demographic description of the mothers at the time of enrollment in NIOS. At the University of Chicago, most mothers were Black (89%), single (82%), unemployed (77%), and reported an annual household income less than \$10,000 (48%). One-third (33%) did not have a high school diploma or G.E.D. Their average age was 24 years and 18% were teens (less than 18 years

old). For about one-half, this was their first child (54%).

Like University of Chicago, mothers at Mount Sinai were similar in age (average age 25 years, 14% teens) and marital status (75% single). However, mothers at Mount Sinai were more likely to be Hispanic (27% vs. 6%,  $p < 0.01$ ,  $p$ -values for comparisons between sites are not shown on Table IV.3), have not graduated from high school (48% vs. 33%,  $p = 0.06$ ), have been unemployed (94% vs. 77%,  $p = 0.04$ ), and had an annual household income less than \$10,000 (70% vs. 48%,  $p = 0.06$ ). They were also more likely to have had a previous birth (65% vs. 46%,  $p = 0.02$ ).

Because the two sites differ on many important demographic characteristics known to influence maternal and

TABLE IV. 3. DEMOGRAPHIC DESCRIPTION OF THE MOTHERS AT THE TIME OF ENROLLMENT IN NIOS

Maternal Demographics	Mount Sinai			University of Chicago			Both Sites			p-value*
	Proj Access n=46	Control n=20	Total n=66	Proj Access n=57	Control n=30	Total n=87	Proj Access n=103	Control n=50	Total n=153	
Average age	26 years	24 years	25 years	24 years	25 years	24 years	25 years	24 years	25 years	0.58
Age group										
Less than 18 years old	13%	15%	14%	23%	10%	18%	18%	12%	16%	0.11
19-35 years old	70%	75%	71%	68%	90%	76%	69%	84%	74%	
Older than 35 years	17%	10%	15%	9%	0%	6%	13%	4%	10%	
Race/ethnicity ^										
Black	65%	76%	69%	85%	97%	89%	76%	90%	81%	0.15
Hispanic	28%	24%	27%	9%	0%	6%	18%	8%	15%	
Other	7%	0%	5%	5%	3%	5%	6%	2%	5%	
Education level ^										
Less than a high school diploma	50%	44%	48%	36%	27%	33%	43%	33%	40%	0.28
High school diploma or G.E.D.	50%	56%	52%	64%	73%	67%	57%	67%	60%	
Marital status ^										
Single	74%	78%	75%	85%	77%	82%	80%	77%	79%	0.88
Divorced, separated, or widowed	7%	0%	5%	0%	7%	15%	3%	4%	3%	
Married	20%	22%	20%	15%	17%	2%	17%	19%	17%	
Lives with infant's father #										
Yes	43%	39%	42%	45%	41%	44%	45%	40%	43%	0.64
No	57%	61%	58%	55%	59%	56%	55%	60%	57%	

Employment status ^																						
Not employed	93%	94%	94%	94%	76%	83%	77%	84%	88%	85%	0.46											
Employed part-time	4%	0%	3%	3%	9%	3%	7%	7%	2%	5%												
Employed full-time	2%	6%	3%	3%	15%	13%	14%	9%	10%	9%												
Annual household income +																						
\$10,000 or less	71%	67%	70%	70%	44%	57%	48%	56%	60%	57%	0.30											
\$10,001-\$20,000	13%	11%	13%	13%	13%	27%	18%	13%	21%	16%												
over \$20,000	11%	11%	11%	11%	27%	17%	24%	20%	15%	18%												
Don't know	4%	11%	6%	6%	16%	0%	11%	11%	4%	9%												
First birth (i.e., primiparous)																						
Yes	37%	30%	35%	35%	56%	50%	54%	48%	42%	46%	0.52											
No	63%	70%	65%	65%	44%	50%	46%	52%	58%	54%												
Kessner's risk for age/parity \$																						
High risk	24%	20%	23%	23%	18%	10%	15%	20%	14%	18%	0.34											
Low risk	76%	80%	77%	77%	82%	90%	85%	80%	86%	82%												

Source: NICU Infant Outcome Study (NIOS)

\* The results are considered statistically significant if the probability of the result (the "p-value") is less than 5% or 0.05. The p-values shown are for statistical comparisons between Project Access and Control groups. Statistical comparisons between each hospital and between groups at each hospital are not shown.

^ 4 mothers/caregivers are missing this information as they did not complete the Demographic questionnaire (n=149: 101 Proj Access, 48 Control)

# 5 mothers/caregivers are missing this information: 4 did not complete the Demographic questionnaire and 1 refused to answer this question (n=148: 101 Project Access, 47 Control)

+ 5 mothers/caregivers are missing this information: 4 did not complete the Demographic questionnaire and 1 refused to answer this question (n=148: 100 Project Access, 48 Control)

§ Based on criteria set down by Kessner DM. Infant Death: An Analysis by Maternal Risk and Health Care, Institute of Medicine, National Academy of Sciences, 1973.

child health, data in this report will be presented separately for each study site, as well as for the two sites combined. However, as evidenced by the final column in Table IV.3, none of the 10 characteristics selected demonstrate any statistical significance (i.e., p-value less than 0.05) either between the Project Access and control groups or between groups at each hospital (p-values not shown on Table IV.3). Thus, the lack of any significant differences suggests that the randomization process was sound and did what it was designed to do: it allocated participants rather uniformly across many characteristics into the two study groups. This theoretically leaves the intervention as the main difference between the groups. Thus, if outcome measures vary between the groups, we would feel comfortable attributing the variation to the intervention.

### 3. PSYCHOSOCIAL PROFILE

In addition to looking at maternal demographics, we also used three standardized psychometric instruments in order to examine the psychosocial profile of the mothers at the time of NIOS enrollment. The three psychometric instruments used are discussed below.

#### *Short Form – 36 (SF-36)*

The SF-36 is a well-validated, widely used instrument that measures a person's perceived mental and physical health status.<sup>15</sup> Used in well-over 1000 studies, the instrument has been found to correlate well with other measures of morbidity and mortality.<sup>16,17</sup> The instrument yields an 8-scale health profile and 2 composite summary scores, the Physical Component Summary (PCS) and Mental Component Summary (MCS). Questions on the SF-36 include: "In general, would you say your health is excellent, very good, good, fair, or poor?" and "During the past four weeks, have you accomplished less than you would like as a result of any emotional problems,

such as feeling depressed or anxious?". Responses to the SF-36 are scored such that a higher score indicates a better state of health. Scores can also be directly compared to published norms for the general population.

#### *Modified MOS Social Support Survey*

This brief social support survey was developed for patients in the Medical Outcomes Study, a two-year study of patients with chronic conditions. It was designed to measure the respondent's level of perceived social support.<sup>18</sup> For example respondents are asked: "How often is each of the following kinds of support available to you if you need it..."

- Someone available to give you good advice in a crisis?
- Someone to show you love and affection?
- Someone to help you with daily chores?"

Each question is rated on a five-point Likert scale ranging from 1—"none of the time" to 5—"all of the time." The survey yields one composite score, the Social Support Index, and four functional support subscales: tangible, emotional, affectionate, and positive social interaction. A higher score indicates more perceived support.

As the original MOS Social Support Survey was designed for use with chronically ill patients, it included several questions not particularly relevant to low-income mothers of high-risk infants. Thus, the NIOS research team replaced several of the tangible subscale items from original MOS Social Support Survey with items that better captured the material support needs of our families. The new tangible subscale items in the Modified MOS Social Support Survey include the following questions: "How often is each of the following kinds of support available to you? Someone to..."

- Watch over your kids for several hours
- Give you a place to stay if you needed it
- Loan you cash if you needed it

- Help take care of you if you were sick
- Help you with daily chores
- Give you advice about your baby if you had questions.”

Questions on the other subscales of the survey (i.e., emotional, affectionate, and positive social interaction subscales) are identical to those on the original MOS Social Support Survey.

*Multidimensional Health Locus of Control (MHLC)*

The MHLC scale was developed to measure the extent of internal and external control perceived by individuals over their health.<sup>19</sup> The MHLC scale is an 18-item measure which is comprised of three dimensions, each containing six items to gauge individuals’ “internal,” “powerful others,” and “chance” loci of control. Each of the items is rated on a six-point Likert scale ranging from 1— “strongly disagree” to 6—“strongly agree” and summed within each dimension to produce total scores for the three domains.

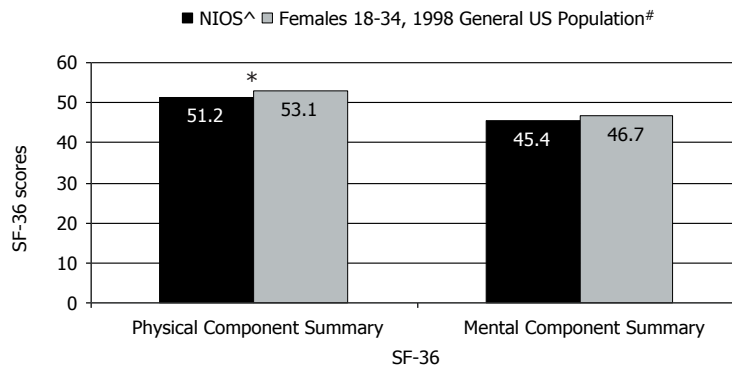
- Internal Locus of Control has been found to predict whether preventive and intervention measures of health care are adopted by individuals (e.g., “I am directly responsible for my health”).
- Chance is a measure of individuals’ perceptions of their ability to

determine their health status and health behaviors rather than it depending upon fate, luck or chance (e.g., “It seems my health is greatly influenced by accidental happenings”).

- Powerful Others is a measure of the individual’s perception of the ability of health care professionals to determine their health status (e.g., “The type of care I receive from other people is what is responsible for how well I recover from an illness”).

Table IV.4 presents the psychosocial profile of mothers at the time of NIOS enrollment. As can be seen from the final column, there are no statistical differences (i.e., p-value less than 0.05) between the study groups, again confirming that the randomization process was successful. However, in order to put the psychosocial profile into context, the NIOS research team felt it was important to compare the scores of NIOS mothers to national normative data (where available), and where national data were not available, to collect our own. To that end, a neonatology fellow at the University of Chicago recruited and interviewed mothers of healthy newborns from the general nursery at University of Chicago. Between October-November 2002, 36 demographically similar mothers of healthy infants were interviewed using the

FIGURE IV. 1.  
PERCEIVED PHYSICAL AND MENTAL HEALTH OF MOTHERS OF NIOS INFANTS COMPARED TO NATIONAL NORMS



Source: NICU Infant Outcomes Study (NIOS)

<sup>^</sup> 6 mothers/caregivers are missing this information: 5 did not complete the SF-36 and 1 skipped several questions, too many to accurately score the PCS and MCS (n=147)

<sup>#</sup> Ware JE and Kosinski M. *SF-36 Physical & Mental Health Summary Scales: A Manual For Users of Version 1*, Second Edition, Lincoln, RI: QualityMetric Incorporated, 2001.

\* 95% Confidence Interval for NIOS mothers (49.62-52.76) does not include the average PCS score for the norms (53.1)

TABLE IV. 4. PSYCHOSOCIAL PROFILE OF MOTHERS AT THE TIME OF NIOS ENROLLMENT

Psychosocial profile	Mount Sinai		University of Chicago		Both Sites		p-value*	
	Proj Access n=46	Control n=18	Proj Access n=54	Control n=30	Proj Access n=100	Control n=48		Total n=148
SF-36 ^								
Physical Component Summary	48.3	50.6	52.3	54.0	50.5	52.7	51.2	0.18
Mental Component Summary	46.4	44.7	44.3	46.1	45.3	45.6	45.4	0.92
Modified MOS Social Support Survey #								
Social Support Index	73.4	67.8	76.6	73.3	75.1	71.3	73.8	0.35
Multidimensional Health Locus of Control†								
Internal	29.2	28.4	29.5	29.5	29.3	29.1	29.3	0.75
Chance	18.4	20.2	20.1	20.3	19.3	20.3	19.6	0.42
Powerful Others	24.9	27.8	23.1	24.6	23.9	24.8	24.2	0.39

Source: NICU Infant Outcome Study (NIOS)

\* The results are considered statistically significant if the probability of the result (the "p-value") is less than 5% or 0.05. The p-values shown are for statistical comparisons between Project Access and Control groups. Statistical comparisons between each hospital and between groups at each hospital are not shown.

^ 6 mothers/caregivers are missing this information: 5 did not complete the SF-36 and 1 skipped several questions, too many to accurately score the PCS and MCS (n=147, 99 Project Access, 48 Control).

# 5 mothers/caregivers are missing this information as they did not complete the Modified MOS Social Support Survey (n=148: 100 Project Access, 48 Control).

+ 5 mothers/caregivers are missing the Internal and Powerful Others loc as they did not complete the MHLCC (n=148: 100 Project Access, 48 Control) and 6 are missing the Chance locus: 5 did not complete the instrument and 1 skipped several questions in the Chance locus, too many to accurately score it (n=147: 99 Project Access, 48 Control).

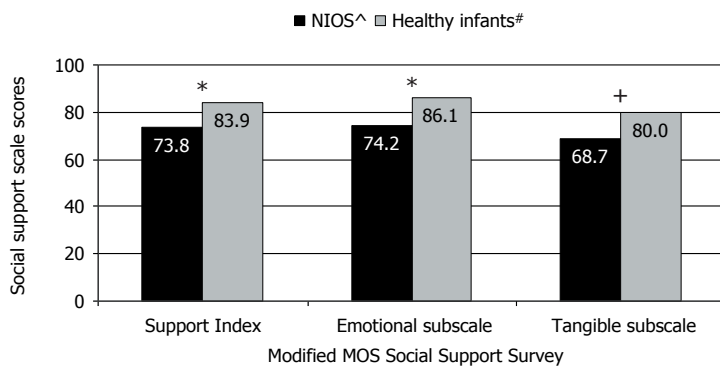


FIGURE IV. 2.  
PERCEIVED SOCIAL  
SUPPORT OF MOTHERS  
OF NIOS INFANTS  
COMPARED TO MOTHERS  
OF HEALTHY NEWBORNS

Source: NICU Infant Outcomes Study (NIOS)

^ 5 mothers/caregivers are missing this information as they did not complete the Modified MOS Social Support Survey (n=148)

# Demographically similar mothers of healthy infants born at University of Chicago (n=36)

\* p<0.01. The results are considered statistically significant if the probability of the result (the "p-value") is less than 5% or 0.05. The p-values shown are for statistical comparisons between the NIOS mothers and mothers of healthy infants.

+ p=0.02

Demographics questionnaire, Modified Social Support Survey, and the CRISYS (described below).

Figure IV.1 presents the perceived physical and mental health (i.e., SF-36) of mothers of NIOS infants compared to national norms. NIOS mothers had significantly poorer physical health as compared to females aged 18 to 34 in the US general population. That is to say, the 95% confidence interval for the physical component summary score (PSC) for NIOS mothers (49.6-52.8) did not include the average PCS score for the norms (53.1). Recall that a higher score indicates a better state of health. However, this difference is probably not clinically significant. The NIOS

mothers also had similar perceived mental health as compared to the norms. The 95% confidence interval for the mental component summary score (MCS) for NIOS mothers (43.3-47.5) includes the average MCS score for the norms (46.7).

Figure IV.2 presents the perceived social support (i.e., Modified MOS Social Support Survey) of mothers of NIOS infants compared to mothers of healthy newborns. NIOS mothers had less social support than mothers of healthy infants (Social Support Index 73.8 vs. 83.9, p<0.01), reporting significantly less emotional and less tangible support than mothers of healthy infants (emotional subscale 74.2 vs. 86.1, p<0.01 and tangible subscale 68.7 vs. 80.0, p=0.02).

Social Support Survey - Tangible support subscale ^	NIOS n=148	Healthy infants n=36	p-value*
Someone to watch over your kids for several hours	59%	69%	0.24
Someone to give you a place to stay if you needed it	72%	83%	0.15
Someone to give you a ride if you needed it	59%	81%	<b>0.02</b>
Someone to loan you cash if you needed it	49%	78%	<b>&lt;0.01</b>
Someone to help take care of you if you were sick	70%	92%	<b>&lt;0.01</b>
Someone to help you with daily chores	50%	67%	<b>0.07</b>
Someone to give you advice about your baby if you had questions	83%	89%	0.39

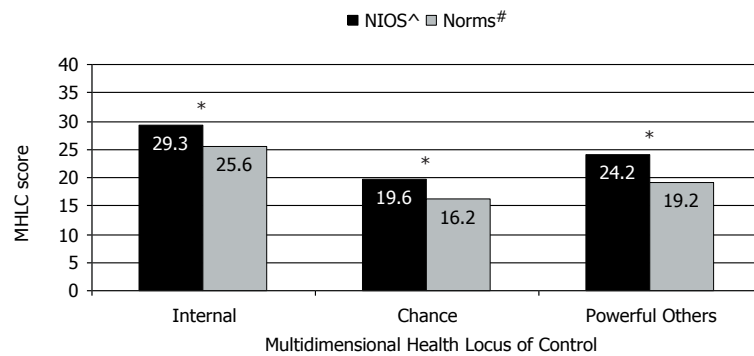
TABLE IV.5.  
TANGIBLE  
SUPPORT SUBSCALE  
OF THE MODIFIED  
MOS SOCIAL  
SUPPORT SURVEY

Source: NICU Infant Outcome Study (NIOS)

\* The results are considered statistically significant if the probability of the result (the "p-value") is less than 5% or 0.05. The p-values shown are for statistical comparisons between the NIOS mothers and mothers of healthy infants.

^ 5 mothers of NIOS infants are missing this information as they did not complete the Modified MOS Social Support Survey (n=148)

FIGURE IV. 3.  
MULTIDIMENSIONAL  
HEALTH LOCUS OF  
CONTROL (MHLC)  
FOR MOTHERS OF  
NIOS INFANTS  
COMPARED TO  
PUBLISHED NORMS FOR  
HEALTHY ADULTS



Source: NICU Infant Outcomes Study (NIOS)

<sup>^</sup> 5 mothers/caregivers are missing the Internal and Powerful Others loci as they did not complete the MHLC (n=148) and 6 are missing the Chance locus: 5 did not complete the instrument and 1 skipped several questions in the Chance locus, too many to accurately score it (n=147)

<sup>#</sup> Wallston KA and Wallston BS. Health locus of control scales. In *Research with Locus of Control Construct (Vol. 1)* (Edited by Lefcourt HM). Academic Press, New York, 1981.

\* 95% Confidence Intervals for the Internal, Chance, and Powerful Others loci of NIOS mothers do not include the average loci scores for the norms

Table IV.5 breaks down the tangible support subscale into its 7 items. Fewer NIOS mothers stated that they had had someone to give them a ride (59% vs. 81%,  $p=0.02$ ), loan them cash (49% vs. 78%,  $p<0.01$ ), take care of them when sick (70% vs. 92%,  $p<0.01$ ), or help with daily chores (50% vs. 67%,  $p=0.07$ ) than mothers of healthy infants. In fact, although not all were statistically significant, NIOS mothers reported that they had less support available to them for all 7 items.

Figure IV.3 presents the MHLC for mothers of NIOS infants compared to published norms for healthy adults. As you can see, NIOS mothers had significantly higher internal, chance, and powerful others loci when compared to a sample of healthy adults (i.e., the 95% confidence intervals for each of three loci did not include the norm). Several studies have demonstrated that a high internal locus of control is associated with the adoption of preventive health measures (e.g., regular exercise and dieting for health reasons)<sup>20,21</sup> and that a combination of both high internal and powerful others loci is associated with engaging in help-seeking behavior (e.g., receiving treatment for depression).<sup>22</sup> That is to say, the instrument has been shown useful in predicting an individual's health behavior, or in our case in predicting

the mother/caregiver's involvement with their child's health care. From our results, NIOS mothers, on average, would likely be receptive to participation in case management activities like those of Project Access.

#### 4. LIFE STRESS

We also felt it was important to obtain a picture of the life stress experienced by the mothers of NIOS infants; thus, we administered the Crisis in Family Systems (CRISYS) instrument at several points in the study. The CRISYS is described below.

##### *Crisis in Family Systems (CRISYS)*

The CRISYS is a measure of contemporary life stressors. It was created to help describe the experiences of vulnerable populations and provides a cross-sectional profile of the contemporary life events (e.g., financial issues, family issues, and work issues) faced by a family.<sup>23</sup> For example, the instrument asks: "Has any of the following events happened to you in the previous six months..."

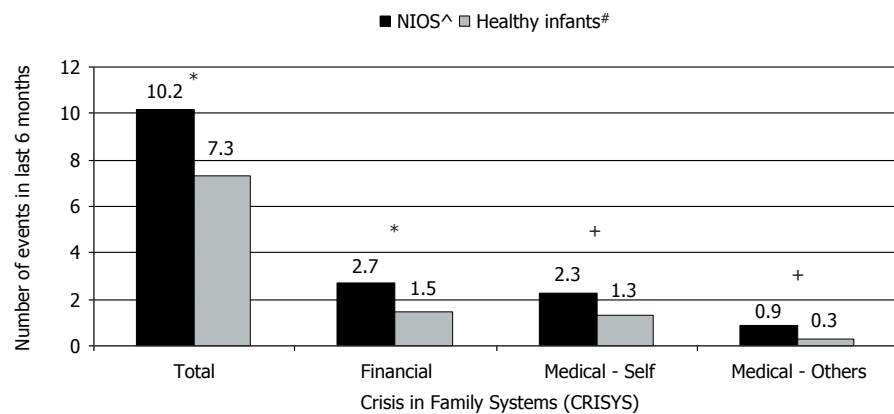
- Did you go without food because you couldn't pay for it?
- Did your child get admitted to the hospital?
- Did you return to school?
- Did you see violence?"



A total of 64 possible events are listed. Results are presented by summing the total number of events experienced in the last 6 months. In addition, the number of events experienced can also be summed for the 11 content domains included in the instrument: financial, legal, career, relationships, medical (self), medical (others), safety in the community, safety in the home, home issues, difficulty with authority, and prejudice. The CRISYS has demonstrated good validity and reliability for adult caregivers in low-income urban areas who have healthy and disabled children.<sup>24</sup>

Figure IV.4 presents the number of stressful life events in the past 6 months (i.e., CRISYS) for mothers of NIOS infants compared to mothers of healthy infants. As can be seen, stressful life events in the previous 6 months were more common for mothers of NIOS infants than mothers of healthy infants (10.2 vs. 7.3 total events,  $p < 0.01$ ). The stressful life events included stress from their difficult pregnancy and infant's illness (2.3 vs. 1.3 medical (self) events,  $p < 0.001$  and 0.9 vs. 0.3 medical (other) events,  $p < 0.001$ ), but it also includes

FIGURE IV.4.  
AVERAGE NUMBER  
OF STRESSFUL LIFE  
EVENTS IN THE PAST 6  
MONTHS FOR MOTHERS  
OF NIOS INFANTS  
COMPARED TO  
MOTHERS OF HEALTHY  
INFANTS



Source: NICU Infant Outcomes Study (NIOS)

^ 4 mothers/cargivers are missing this information as they did not complete the CRISYS (n=149)

# Demographically similar mothers of healthy infants born at the University of Chicago (n=36)

\*  $p < 0.01$ . The results are considered statistically significant if the probability of the result (the "p-value") is less than 5% or 0.05. The p-values shown are for statistical comparisons between the NIOS mothers and mothers of healthy infants.

+  $p < 0.001$

TABLE IV.6. FINANCIAL DOMAIN OF THE CRISYS

Crisis in Family Systems - Financial domain ^	NIOS n=149	Healthy infants n=36	p-value*
Income increased by alot	13%	14%	0.79
Went deeply into debt	34%	25%	0.29
Income decreased by alot	40%	28%	0.17
Went without food	12%	6%	0.37
Went without clothing	26%	6%	<b>&lt;0.01</b>
Missed rent payments	28%	8%	<b>0.02</b>
Utilities threaten to cut off service	30%	17%	0.12
Utilities were turned off	21%	8%	<b>0.07</b>
Went without furniture	20%	8%	<b>0.10</b>
Went without appliances	13%	3%	<b>0.08</b>
Miss medical appointments because no transportation to get there	32%	31%	0.85

Source: NICU Infant Outcome Study (NIOS)

\* The results are considered statistically significant if the probability of the result (the "p-value") is less than 5% or 0.05. The p-values shown are for statistical comparisons between the NIOS mothers and mothers of healthy infants.

^ 4 mothers of NIOS infants are missing this information as they did not complete the CRISYS (n=149)

events not related to their infant's medical condition. Specifically, these mothers appear to have more financial stress (2.7 vs. 1.5 financial events,  $p < 0.01$ ). Table IV.6 breaks the financial domain into its 11-items. More NIOS mothers reported that they missed rent payments (28% vs. 8%,  $p = 0.02$ ), had their utilities shut off (21% vs. 8%,  $p = 0.07$ ), and went without clothing from lack of money (26% vs. 6%,  $p < 0.01$ ). Although not statistically different from mothers of healthy infants, an appalling 12% of NIOS mothers went without food because they couldn't pay for it.

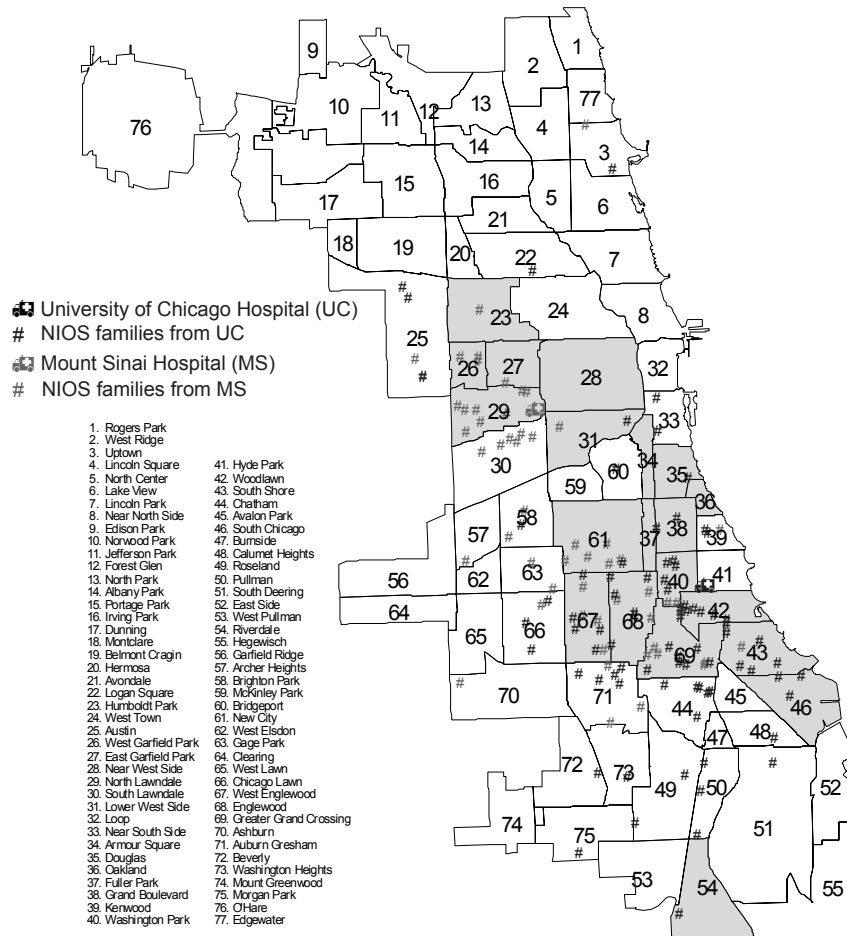
From the life stress data, as well as the demographic data and psychosocial profiles in the previous sections, it is possible to conclude that in addition to being poor and undereducated, mothers

in our study commonly faced additional stressful events and often had less support than similarly impoverished mothers of healthy newborn infants. All of this confirms that this is indeed a high-need cohort.

## 5. HOUSING AND NEIGHBORHOOD CONTEXT

Lack of safe affordable housing was one of the most significant issues facing families. When they were asked near the time of NICU discharge what issues they expected to need help with now that they had a new baby, 69% stated that they expected that they would need help finding housing. As Chicago is in the midst of an affordable housing crisis,<sup>25,26,27</sup> this response is not surprising. It is estimated that there is only one affordable unit for every two renters in Chicago.<sup>28</sup> Some

FIGURE IV.5  
CHICAGO'S 20  
POOREST COMMUNITY  
AREAS (SHADED)  
AND THE RESIDENCE  
OF FAMILIES AT TIME  
OF ENROLLMENT IN  
NIOS



Source: NICU Infant Outcomes Study (NIOS)

of the reasons for this crisis include: the Chicago Housing Authority (CHA) is tearing down 18,000 public housing units<sup>29</sup> faster than they are rebuilding replacement units (e.g., in 2001, 2,293 units were demolished and only 71 new units were built);<sup>30</sup> few housing subsidy programs, like Section 8, are available (e.g., Section 8 has a waiting list of approximately 30,000 and has been “closed” to new applicants for several years);<sup>31</sup> and gentrification is pushing low-income families farther from the city center and farther from convenient public transportation. In addition to the lack of affordable housing, the housing stock is 3 times older in Chicago than the national average.<sup>32</sup>

This lack of affordable, safe housing may take its greatest toll on low-income mothers and their medically high-risk infants. For example, serious health risks may result from poor housing stock such as asthma or lead poisoning and unsafe areas pose significant barriers to accessing both health care and social services. In addition, unstable home environments may lead to missed medical appointments and failure to apply for public benefits or social services. Thus, we felt it was important to describe the housing needs for our cohort of NIOS/Project Access families in order to better advocate on behalf of these families on issues related to housing.

Figure IV.5 presents the location of families at the time of their enrollment in NIOS. Each # symbol represents the location of a family superimposed upon a map of the 77 official community areas in Chicago. The 20 poorest areas, that is, those with the lowest median household incomes as determined by the 2000 Census, are shaded gray. As expected, most of the 20 poorest communities are on the south and west sides of the city, areas that are overwhelmingly Black and Hispanic. About one-half of NIOS families (54%), live in one of the 20 poorest community areas. From this map we can also see that 39% of NIOS families live within 3 miles of their hospital of enrollment, but the majority

TABLE IV.7. HOUSING NEEDS AND NEIGHBORHOOD CHARACTERISTICS FOR FAMILIES AT THE TIME OF ENROLLMENT IN NIOS

Housing and Neighborhood Characteristics	NIOS n=153
Live within 3 miles of hospital of enrollment	39%
Live in one of the 20 poorest Community Areas in Chicago	54%
Average number of years living at current address*	4 years
Moved in the last year*	32%
Average number of people living in the household	5 persons
Housing situation*	
Owns or jointly owns home	4%
Rents from private individual/property company	41%
Rents from a relative	12%
Lives in CHA or HUD housing	6%
Lives in someone else's home but contributes money	20%
Lives rent-free in someone else's home	17%
Live in overcrowded housing*^	27%
Live in poor housing conditions*+	21%
Average household pays in rent or mortgage <sup>#</sup>	\$482
Receive subsidies or vouchers to help pay for rent (e.g., section 8)*	9%
Find it difficult to pay rent or mortgage each month*	53%
Currently behind on rent or mortgage payments*	17%
Lost housing in last 6 months <sup>\$</sup>	8%
Heard violence outside their home in the last 6 months (e.g., gun shots) <sup>\$</sup>	34%
Do not own a car <sup>~</sup>	59%

Source: NICU Infant Outcome Study (NIOS)

\* 4 mothers/caregivers are missing this information as they did not complete the Housing module (n=143)

^ Overcrowded housing is defined as having 3 or more persons per bedroom

+ Based in part on the Housing Deprivation Index developed by Marsh et al. Housing deprivation and health: a longitudinal study analysis. *Housing Studies*. 2000;15(3):411-428. Asks 12 questions such as, "Do you have any of the following problems with your home... shortage of space, leaky roof, cockroaches or insects, broken or stopped up plumbing...?" Those with three or more problems are designated as living in poor housing conditions.

# 33 mother/caregivers were not included in this average: 10 did not complete the Housing module and 23 did not know the amount their household pays in rent/mortgage (n=120)

\$ 4 mothers/caregivers are missing this information as they did not complete the CRISYS questionnaire (n=149)

~ 3 mothers/caregivers are missing this information as they did not complete the Social Services Survey (n=150)

of families must travel across the city in order to attend outpatient, high-risk follow-up and specialty appointments. Perhaps adding another burden in their already stressful lives?

Table IV.7 describes the housing needs and neighborhood characteristics for families at the time of enrollment in NIOS. Many of the families were in unsafe or substandard housing. For

example: 27% lived in crowded housing (defined as 3 or more persons per bedroom); 21% lived in poor housing conditions with 3 or more major problems such as leaky roof, broken or stopped up plumbing, too little heat, etc.; 23% had pests like cockroaches or mice; and 34% heard gunfire outside their home in the last 6 months. In addition, most families were in unstable housing situations: 32% moved at least once in the last year, 44% lived in someone else's home, 53% found it difficult to pay rent each month, and 17% were currently behind on rent payments. Few were receiving any kind of housing assistance: only 6% lived in public housing and only 9% were receiving a subsidy, like Section 8, to help pay for rent.

Some implications of unstable housing could include: 1) frequent moves making it hard for medical providers to keep track of patients and remind them of appointments, and 2) changing addresses resulting in missed notices regarding public benefits or even missed checks. When we looked at whether living in unstable or unsafe housing was associated with poor compliance with medical appointments, we found that families who moved at least once in the previous year were less compliant with their infants' medical care in the first 6 months post-NICU discharge. Specifically, the group that moved at least once in the last year missed 93 (24%) of 393 scheduled appointments at the hospitals' high-risk outpatient clinic vs. 79 (16%) of 496,  $p < 0.01$ . We hope to explore these data further.

#### 6. THOSE LOST TO THE STUDY

Of the 153 families who enrolled in NIOS, 108 (71%) completed the study while 45 (29%) were lost to the study. Figure III.1 summarizes the reasons families were lost to the study and Figures III.2 and III.3 presents this same data by institution. A family was considered lost to the study if they did not complete the majority of the questions on the 12

months post-NICU discharge interview. Reasons families were lost to the study included: 9 families actively withdrew from the study (e.g., moved out of state, no longer wished to participate in the study, changed pediatricians), 9 infants died before reaching the 12 month post-NICU interview, 4 infants were placed into DCFS custody, and 23 were lost to follow-up (i.e., the research assistant was not able to locate the mother/caregiver in order to complete the interview).

This represents a 29% lost to study rate, which is not at all unusual for a population like the one being studied.<sup>33,34</sup> A related issue is the extent to which those who were lost to the study differed from those who completed the study. This question may be examined by the data presented in Table IV.8, which presents 12 characteristics of those who completed the study compared to those who were lost to the study. As can be seen from the p-values presented in the last column, none of the characteristics associated with the study itself, the infants' medical condition, or maternal demographics at the time of enrollment were statistically different between families that completed the study and those who were lost to the study. Interestingly, two differences approach significance (i.e., 0.05). These are the perceived mental health of the mother at time of enrollment, as measured by the Mental Component Summary (MCS) score of the SF-36 and her perceived social support, as measured by the Social Support Index of the Modified MOS Social Support Survey. Mothers who were lost to the study had poorer mental health (41.7 vs. 46.7,  $p = 0.04$ ) and less social support (67.9 vs. 76.0,  $p = 0.10$ ) at the time of enrollment in the study as compared to mothers who completed the study.

However, taken together these 12 variables indicate that those who were lost to the study were not a selected group of people but rather were representative of the larger group. Thus, there is little

Selected characteristics	Completed n=108	Lost to Study n=45	p-value*
<b>STUDY CHARACTERISTICS</b>			
Hospital of enrollment			
Mount Sinai	43%	44%	0.83
University of Chicago	57%	56%	
Study group			
Proj Access	31%	36%	0.62
Control	69%	64%	
<b>INFANT HEALTH</b>			
Primary medical criteria for enrollment			
Very low birthweight	78%	80%	0.76
At risk for adverse neurological outcomes	22%	20%	
Complex needs at discharge <sup>+</sup>			
Yes	65%	67%	0.83
No	35%	33%	
<b>MATERNAL DEMOGRAPHICS</b>			
Average age	24 years	25 years	0.74
Race/ethnicity <sup>#</sup>			
Black	79%	85%	0.57
Hispanic	17%	10%	
Other	5%	5%	
Education level <sup>#</sup>			
Less than a high school diploma	43%	32%	0.23
High school diploma or G.E.D.	57%	68%	
Marital status <sup>#</sup>			
Single	79%	80%	0.72
Divorced, separated, or widowed	3%	5%	
Married	19%	15%	
Employment status <sup>#</sup>			
Not employed	83%	90%	0.29
Employed	17%	10%	
Annual household income <sup>\$</sup>			
\$10,000 or less	55%	63%	0.63
\$10,001-\$20,000	15%	17%	
over \$20,000	21%	12%	
Don't know	9%	7%	
<b>PSYCHOSOCIAL PROFILE</b>			
Perceived physical and mental health <sup>~</sup>			
Physical Component Summary	51.3	51.0	0.88
Mental Component Summary	46.7	41.7	<b>0.04</b>
Perceived social support <sup>**</sup>			
Social Support Index	76.0	67.9	<b>0.10</b>

TABLE IV.8.  
CHARACTERISTICS  
OF THOSE WHO  
COMPLETED THE  
STUDY COMPARED  
TO THOSE WHO  
WERE LOST TO THE  
STUDY<sup>^</sup>

Source: NICU Infant Outcome Study (NIOS)

- <sup>^</sup> NIOS families are designated as 'Completed' if they completed the majority of the questions on the 12 month post-discharge interview, otherwise they are designated as 'Lost to Study'.
- \* The results are considered statistically significant if the probability of the result (the "p-value") is less than 5% or 0.05. The p-values shown are for statistical comparisons between Completed and Lost to Study groups.
- <sup>+</sup> Complex needs at discharge include one or more of the following: 1) the need for home equipment such as oxygen and/or home apnea monitoring, 2) the requirement of nasogastric/gastric tube feedings, or 3) 3 or more subspecialty follow-up appointments. 3 infants are missing this information (n=150).
- <sup>#</sup> 4 mothers/caregivers are missing this information as they did not complete the Demographics questionnaire (n=149)
- <sup>\$</sup> 5 mothers/caregivers are missing this information: 4 did not complete the Demographics questionnaire and 1 refused to answer this question (n=148)
- <sup>~</sup> 6 mothers/caregivers are missing this information: 5 did not complete the SF-36 and 1 skipped several questions too many to accurately score the PCS and MCS (n=147)
- <sup>\*\*</sup> 5 mothers/caregivers are missing this information as they did not complete the Modified Social Support Survey (n=148)

evidence that those families that did not complete the study were markedly different than those who did complete the study. In other words, although losing these 45 families certainly diminished the power of our study, it likely did not bias our findings.

**B. IMPLEMENTATION OF THE PROJECT ACCESS INTERVENTION**

Another important ‘result’ of NIOS has been a detailed description of how the Project Access intervention was implemented. Throughout the service delivery period, the case managers and attorney kept detailed records of their time spent working with project families. As part of this process, they developed case notes on each client recording their interactions with the family, in person and over the phone, and their work on behalf of each family with outside agencies or programs. They also kept detailed time sheets that described both how and where the case managers and attorney were spending most of their time. Not surprisingly, some valuable information was abstracted from these records and is described below.

There were 103 families randomly assigned to receive Project Access services. On average, these families received services for 12 months (ranging

from 2 days to 21 months), with most (82%) being active clients for at least 9 months. At the time of case closure, the average infant was 13 months old.

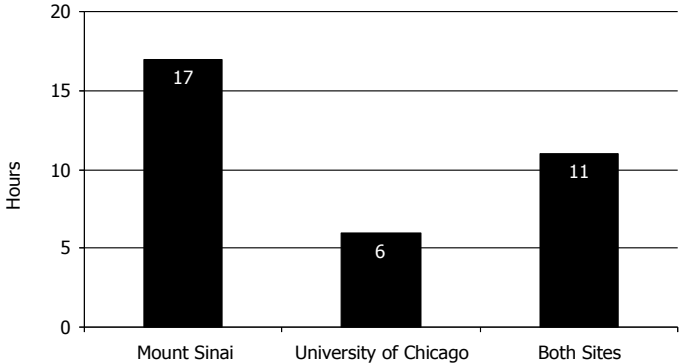
During the 12 months that most project families received services, the case managers’ time on their cases varied between the two hospital sites. As described in detail in the previous section, the apparent differences between the two hospitals’ case management models is attributable to differences that emerged at each institution during the project period. Consequently, these differences impacted how the project case managers spent their time and are reflected in the following results.

As Figure IV.6 shows, case managers spent an average of 11 hours working directly with each family.<sup>‡</sup> When this is broken down by site, a distinction emerges with the Mount Sinai case manager averaging 17 hours per family and the University of Chicago case manager averaging 6 hours per family.

These site differences continue to be apparent when we look at the type of visits the case managers had with participating families. Figure IV.7 shows that on average, the case managers met face-to-face with families 11 times throughout their 12 months of service. However, when we look at each hospital

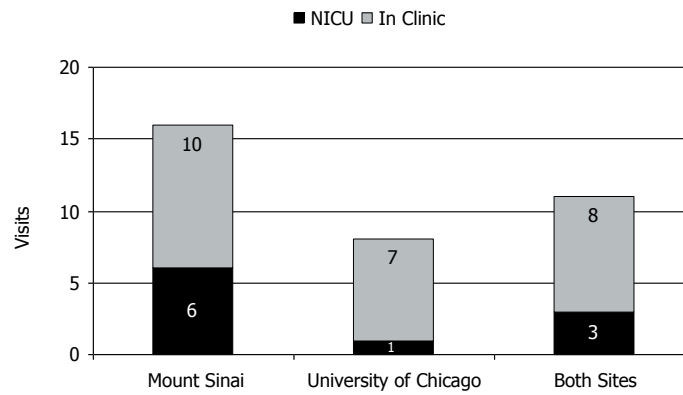
<sup>‡</sup> This only includes “direct service time” provided by the case managers to clients. This time alone does not give an accurate representation of the total staff time required by model.

**FIGURE IV.6.**  
AVERAGE  
NUMBER OF CASE  
MANAGEMENT  
HOURS SPENT  
WORKING DIRECTLY  
WITH PROJECT  
ACCESS FAMILIES



Source: NICU Infant Outcomes Study (NIOS)

FIGURE IV.7.  
AVERAGE NUMBER  
OF FACE-TO-FACE  
VISITS WITH THE  
PROJECT ACCESS CASE  
MANAGER

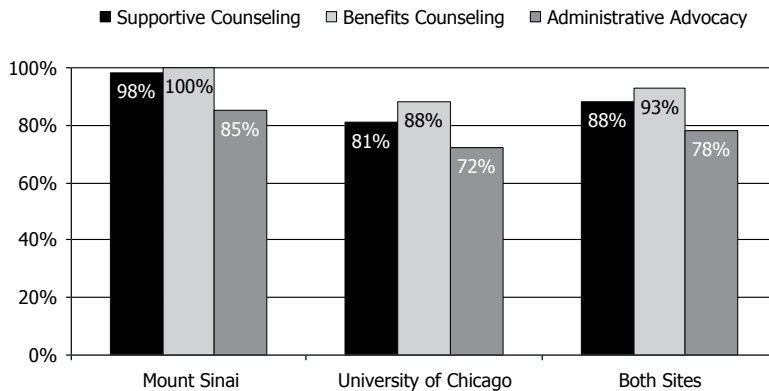


Source: NICU Infant Outcomes Study (NIOS)

site we see that the average number of Mount Sinai face-to-face visits was 16, with 6 of those visits in the NICU and the remaining 10 in the outpatient clinic. At University of Chicago on the other hand, the case manager averaged 8 face-to-face visits with just 1 of those taking place in the NICU and the other 7 in the outpatient clinic.

Figure IV.8 shows the types of services case managers provided to Project Access families during their participation in the program. For instance, 88% of families received supportive counseling from their case managers, 93% received benefits counseling, and 78% received administrative advocacy or direct assistance working with the various agencies responsible for their relevant

benefits and service programs. Because administrative advocacy was such an important component of the project, it is worth looking more specifically at which programs required the most administrative advocacy from case managers. Table IV.9, which is divided into the various program areas targeted by Project Access, shows the number of project families who required administrative advocacy within these programs. As you can see, almost one-half needed administrative advocacy assistance within the SSI program (50/103 families or 49%). Similarly, almost one-half needed administrative advocacy assistance for the EI program (47/103 or 46%). A smaller number or about one quarter required administrative advocacy when trying to secure medical



Source: NICU Infant Outcomes Study (NIOS)

FIGURE IV.8.  
PERCENT OF  
PROJECT ACCESS  
FAMILIES RECEIVING  
SPECIFIC CASE  
MANAGEMENT  
SERVICES  
DURING THEIR  
PARTICIPATION IN  
THE PROGRAM

TABLE IV.9.

NUMBER OF  
PROJECT FAMILIES  
WHO REQUIRED  
ADMINISTRATIVE  
ADVOCACY WITHIN  
SPECIFIC PROGRAMS

	Mount Sinai n=46	U. of Chicago n=57	Both sites n=103
Supplemental Security Income (SSI)	23	27	50
Early Intervention (EI)	19	28	47
Medicaid/Kidcare or other medical insurance	17	9	26
Medical care	3	10	13
Landlord/tenant or housing issues	5	4	9
Transportation	5	3	8
DCFS	3	5	8
Temporary Assistance for Needy Families (TANF)	7	0	7
WIC	1	5	6
Other	4	5	9

Source: NICU Infant Outcome Study (NIOS)

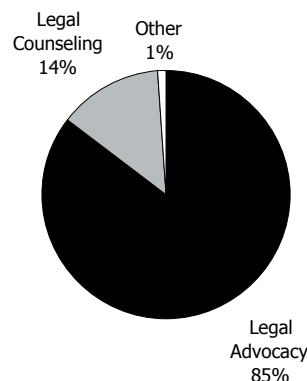
coverage (26/103 or 25%). Interestingly enough, another site difference emerged when looking at the case managers' administrative advocacy results. The nurse case manager at University of Chicago did more administrative advocacy around medical care issues (e.g., appointments, equipment, medicines) for families than the social worker case manager at Mount Sinai (10/57 or 18% vs. 3/46 or 7%). As mentioned earlier, this too may be attributable to the institutional differences described above and specifically the case manager's differing educational backgrounds.

Like the Project Access case managers, the attorney also kept detailed records of her interactions with project participants.

She spent an average of 9 hours working directly with each family. This included an average of 3 face-to-face visits with the family, typically conducted in one of the hospitals' outpatient clinics.

When we look at her time more specifically, we can see where most project families required legal assistance. As described above in the section outlining the project's legal services model, the attorney's time was generally divided into two categories of service provision, legal counseling and legal advocacy. Figure IV.9 shows the percent of time the Project Access attorney spent on each of these specific activities. In fact, 85% of her time working directly with families was spent on legal advocacy, 14% on legal

FIGURE IV.9.  
PERCENT OF TIME  
THE PROJECT  
ACCESS ATTORNEY  
SPENT WORKING  
DIRECTLY WITH  
FAMILIES ON LEGAL  
COUNSELING AND  
LEGAL ADVOCACY



Source: NICU Infant Outcomes Study (NIOS)



counseling and <1% on other activities.

When we look at how that time is attributed to project participants, we see that among the 103 Project Access families, 17% required legal counseling and 70% required legal advocacy to receive the benefits or services to which they were legally entitled. Bear in mind, that any family who received legal advocacy would also necessarily receive legal counseling, as legal advocacy could not be provided without conducting some initial legal counseling.

Not surprisingly, the attorney used legal advocacy to help families access a wide range of services. These included: Supplemental Security Income (SSI) where she used legal advocacy for 51 of the 77 families who were likely eligible for the program (66%); Temporary Assistance for Needy Families (TANF) where legal advocacy was provided in 22/50 cases (44%); Medicaid/KidCare or medical insurance required legal advocacy in 36/103 cases (35%); food stamps required the attorney to provide legal advocacy for 19/77 families (25%); and the EI program required legal advocacy for 10/84 families (12%). One measure of the overall success of this legal services model can be seen through these results in that legal advocacy resulted in receipt of benefits in 143 of the 150 interventions made by the lawyer or 95% of the total cases.

Lastly, we looked at client satisfaction with the Project Access intervention. At the end of the study, Project Access families completed a brief interview with the research assistant on how they felt about the service they received from the Project Access case manager and lawyer, and whether there were ways they could have been helped more. Responses from the families were overwhelmingly positive. 85% said that overall their experience with Project Access was positive (57/67), 13% stated it was neutral (9/67), and 1% said it was negative (1/67). 99% said they received

enough information about the services and programs available to them (67/68). When asked what other services and programs they could have used help with, housing was the most frequent response.

Some of the comments from project families included:

- “I’m very glad they had the Project Access going. It’s a very good idea. I’m grateful for that.”
- “They did everything to keep me focused and serviced me the best way they knew how.”
- “They did everything I needed them to do. They returned calls the same day. All in all just a great group of people.”
- “I had the help that I needed. Thank you!”

### C. RESULTS BY SPECIFIC OUTCOME MEASURE

As noted in the Methodology section, the evaluation of Project Access targeted four specific outcome measures:

1. Receipt of social services and benefits;
2. Parental compliance with post-discharge care;
3. Infant health and development; and
4. Maternal/infant quality of life.

For each of the four outcome measures above, we will present a brief rationale for choosing it, detail some of the specific activities of the intervention that addressed it, describe how it is measured, present the results, and finally, discuss some of the implications of our findings.

#### 1. RECEIPT OF SOCIAL SERVICES AND BENEFITS

Early on, when utilization of and ability to access social services was selected as an outcome for the evaluation of Project Access, it was seen as one with the most potential for impact through case management and legal services. As a result, much of the work of the Project Access case managers and attorney centered on receipt of social services. The case managers and attorney educated

families on benefits and services available, as well as, provided assistance completing benefit/service applications. Assistance with the application could include a range of activities depending on the program – everything from education on the program, to assistance in getting an appointment to file an application at the Department of Human Services (DHS) office, to referrals for Early Intervention (EI) services, and even working to bring agency representatives onsite to the hospitals to complete applications as the Project Access team did with the Social Security Administration (SSA) and the Supplemental Security Income (SSI) program (discussed in detail in the following section). In addition, when necessary, legal advocacy was provided to families. Legal advocacy included a range of activities such as phone calls to relevant government agencies, letters on a client’s behalf, even providing representation at a hearing or another appeal proceeding.

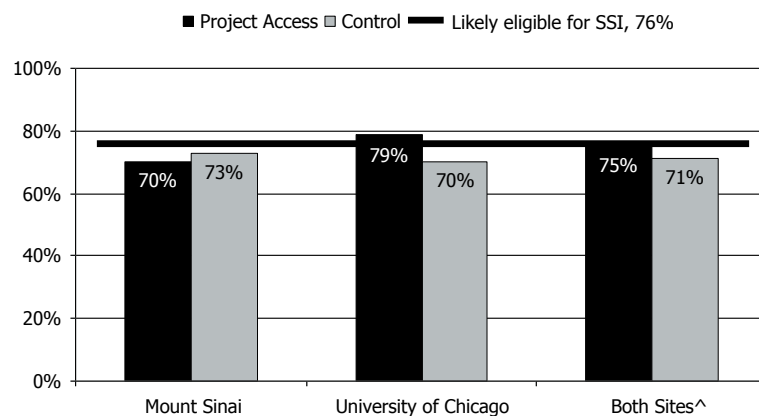
To measure receipt of social services and benefits, every three months post-NICU discharge, the families were asked by the NIOS research assistant whether they were receiving a particular social service or benefit (e.g., “Are you getting a Supplemental Security Income, SSI, SSDI, or a Social Security check for your baby?”).

#### SUPPLEMENTAL SECURITY INCOME (SSI)

Figure IV.10 presents the percent of Project Access families receiving SSI for their infant at 12 months post-NICU discharge compared to control families. The line on Figure IV.10 represents the percent of families whose infants were likely eligible for the program. The Project Access attorney made an estimate of likely eligibility using the information she had for Project Access families (e.g., household income, infant’s medical diagnoses, etc.). In both groups, almost all infants who were likely eligible for SSI were receiving a check and there is no statistically significant difference between Project Access families and control families on receipt of this benefit (75% vs. 71%,  $p=0.63$ ). We can also see that 100% of Project Access families who were likely eligible were receiving SSI checks for their infants.

In other words, both groups received SSI benefits in comparable numbers and in effect all infants eligible were receiving it. This finding is most likely due to the extensive work of Project Access on advocacy with SSA (discussed in the following Section). Much of this work began during Project Access’s pilot period. As soon as the project’s pilot phase began, the project team began educating all NICU and clinic staff on

FIGURE IV.10. PERCENT OF PROJECT ACCESS FAMILIES RECEIVING SUPPLEMENTAL SECURITY INCOME (SSI) FOR THEIR INFANT AT 12 MONTHS POST-NICU DISCHARGE COMPARED TO CONTROL FAMILIES\*



Source: NICU Infant Outcomes Study (NIOS)

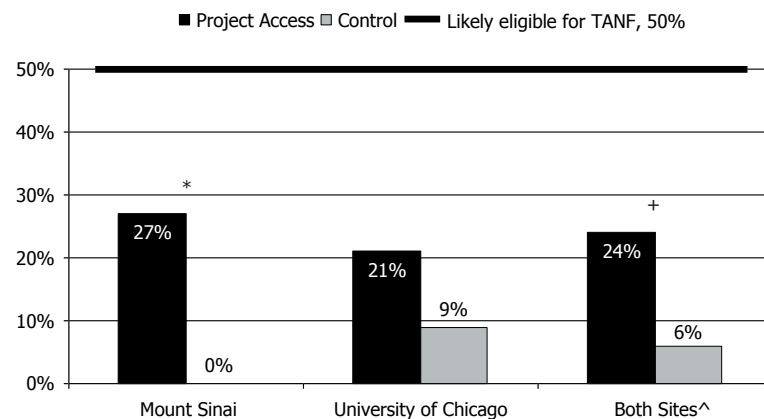
^ 47 families are missing this information: 44 were 'Lost to Study' and 3 did not complete the Social Services Survey at their final interview (n=106, 72 Project Access, 34 Control)

\* None of the statistical comparisons between the Project Access and Control groups demonstrate statistical significance (i.e., none of the p-values are less than 0.05); thus, p-values are not shown.

SSI eligibility requirements and application processes. In addition, the team also spent significant time working with SSA to implement a streamlined application system for these infants. This not only simplified the application process, but also reduced the amount of time it took for families to receive benefits. Consequently, the project team's early interventions into the SSI application process benefited the entire NICU population at both participating hospitals.

the attorney's information from Project Access families. As is evident from this chart, Project Access families were four times more likely to be receiving some other cash benefit like TANF than control families (24% vs. 6% were getting another cash benefit respectively). This result was statistically significant (i.e.,  $p=0.03$ ) between groups at both sites combined and approached significance between groups at Mount Sinai ( $p=0.08$ ).

FIGURE IV.11. PERCENT OF PROJECT ACCESS FAMILIES RECEIVING SOME OTHER CASH BENEFIT AT 12 MONTHS POST-NICU DISCHARGE COMPARED TO CONTROL FAMILIES



Source: NICU Infant Outcomes Study (NIOS)

<sup>^</sup> 47 families are missing this information: 44 were 'Lost to Study' and 3 did not complete the Social Services Survey at their final interview (n=106, 72 Project Access, 34 Control)

\*  $p=0.08$ . The results are considered statistically significant if the probability of the result (the "p-value") is less than 5% or 0.05. The p-values shown are for statistical comparisons between the Project Access and Control groups.

+  $p=0.03$

#### TEMPORARY ASSISTANCE TO NEEDY FAMILIES (TANF)

Figure IV.11 presents the percent of Project Access families receiving some other cash benefit at 12 months post-NICU discharge compared to control families. The cash benefits represented here are primarily Temporary Assistance for Needy Families (TANF) benefits (17 out of 19 families getting other cash benefits), but could also include other benefit programs such as: worker's compensation (0/19), unemployment insurance (0/19), and/or SSI for the mother/caregiver (2/19). The line on Figure IV.11 is an estimate of those likely eligible for TANF, again estimated using

Despite the positive results shown for project participants both groups were actually accessing TANF benefits at a much lower rate than were likely eligible. In fact, one-half of all project families were likely eligible for TANF, but only 16 of the 72 Project Access families (22%) were receiving it and only 1 of the 34 control families (3%) was receiving TANF.

As the results show, Project Access families received more other cash benefits, but the entire group was receiving these benefits at a much lower rate than should be eligible. Several factors may explain this. First, mothers were generally unaware that their high-risk infant qualified them for the TANF

medical exemption for caregivers who are forced to stay home to provide for a sick family member. This exemption not only excuses them from the otherwise required participation in the TANF job program, but it also stops their TANF 60 month clock. This means that any benefits these mothers receive while they have the medical exemption will not be included in their 60 month lifetime limit on TANF payments. Second, there is also a common misconception that families with children on SSI are not eligible for TANF. In fact, infants receiving SSI benefits cannot be included in a TANF case, but other eligible family members may still receive cash benefits. Finally, applying for and retaining TANF benefits can be extremely complicated and, in fact, the Department of Human Services (DHS) program rules often discourage eligible families from applying. As a result, mothers would often rather forgo cash benefits all together rather than try to comply with the program's participation requirements.

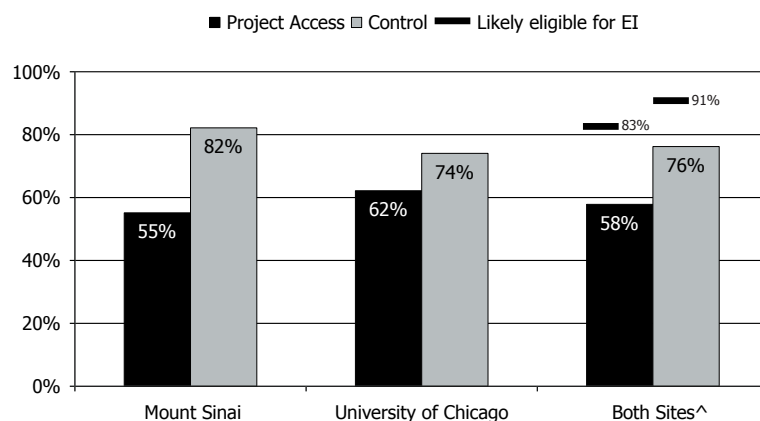
Project Access recognized these barriers to cash assistance and served as a resource for its participating families, providing valuable education and advocacy for them within the TANF system. Case managers and the attorney worked to ensure that families understood

their rights and responsibilities within the program. This included helping families obtain TANF medical exemptions. It also included ongoing assistance in navigating the complex DHS system. Perhaps of most benefit to project families was access to an advocate who could step in and protect the families' interests with DHS personnel when they had difficulty access or retaining their TANF benefits.

#### EARLY INTERVENTION (EI)

Figure IV.12 presents the percent of Project Access families receiving Early Intervention (EI) services for their infants at 12 months post-NICU discharge compared to control families. As can be seen, more control families were receiving EI services than Project Access families and this difference approaches statistical significance (58% Project Access vs. 76% controls,  $p=0.07$ ), but more control families were also likely eligible for EI (83% of Project Access vs. 91% controls). In this case, eligibility was estimated by the case managers reviewing the infants' medical history and looking at information such as birthweight, developmental delays, and doctor referrals to EI. Notably, again, both groups were accessing EI services at a lower rate than should be based on eligibility.

FIGURE IV.12.  
PERCENT OF PROJECT ACCESS FAMILIES RECEIVING EARLY INTERVENTION (EI) SERVICES FOR THEIR INFANTS AT 12 MONTHS POST-NICU DISCHARGE COMPARED TO CONTROL FAMILIES\*



Source: NICU Infant Outcomes Study (NIOS)

<sup>^</sup> 47 families are missing this information: 44 were 'Lost to Study' and 3 did not complete the Social Services Survey at their final interview (n=106, 72 Project Access, 34 Control)

\* None of the statistical comparisons between the Project Access and Control groups demonstrate statistical significance (i.e., none of the p-values are less than 0.05); thus, p-values are not shown.

The data shows that families have difficulty accessing EI services and that the Project Access intervention was not successful in increasing participation rates in the EI program. Client experiences suggest several possible reasons why families do not access EI services.

- *Families do not understand their children's need for services.* In fact, families of small infants do not always recognize delays. Even premature, high-risk infants do the same basic things that all infants do – eat, sleep, etc. Therefore, families often fail to appreciate developmental delays early on because they are not as recognizable as they are when the child grows older. However, failing to treat delays early on often places these children at greater risk when they are older and requires more treatment to correct.
- *Families are already overwhelmed by their situation.* Many of these infants require follow-up medical care from a large range of doctors and therapists. In addition, they are also referred to numerous public benefit programs and social services. All of that combined with any additional obligations these mothers may have to older children or other family members can leave them fairly overwhelmed by their situation. This compromises their ability to participate in every program that their child is referred to.
- *The program is not mandatory.* The EI program is voluntary and often mothers say that they will access the program, but don't think it's necessary right now. This is especially true if, as mentioned earlier, the mother has not yet focused on her infant's long-term needs.
- *There is no cash benefit associated with program.* EI is a program that provides therapeutic services and as a result, there is no cash benefit associated with the program. Because of that, many families will prioritize

it lower than programs that will assist them in meeting their basic needs.

- *Unstable housing makes it difficult for therapists to be in the home.* A large portion of the Project Access/NIOS population lives in someone else's home or moves around frequently resulting in very unstable housing situations. This makes it hard to invite therapists into the home each week to provide services. This also often makes it difficult for therapists to keep track of families when their addresses and phone number are continually changing. As a result of this mobility, families are often dropped from the EI system simply because they are not easily located to receive continuing services.
- *There is no uniform process for how the EI system reaches out to families.* Each different Child and Family Connections agency (CFC) uses a different method of contacting families after referral to the program. Some agencies contact families by phone to schedule an assessment while others send letters asking families to contact them for an appointment. This can considerably delay a child's treatment plan by slowing the time between referral, assessment and actual receipt of services.

The results we are reporting suggest that this model was not effective in improving access to EI services. However, what we have learned from this data and how it is being used to advocate for better services for these families has been invaluable. In other words, even negative program results can lead to systemic advocacy successes. We will discuss this in more depth later in our report when we talk about lessons learned.

#### RESULTS FROM OTHER PUBLIC BENEFIT PROGRAMS

In addition to the programs specifically mentioned above, Project Access also assisted families with programs like:

KidCare, Food Stamps, and WIC. Data from these programs did not reveal significant differences, as participating families were no more likely to be receiving these benefits at 12 months post-NICU discharge than control families. Practically all families had some form of health insurance for their infant (94% Project Access vs. 100% controls,  $p=0.30$ ), most were accessing WIC services (89% vs. 94%,  $p=0.50$ ), and about two-thirds were receiving Food Stamps (66% vs. 61%,  $p=0.58$ ).

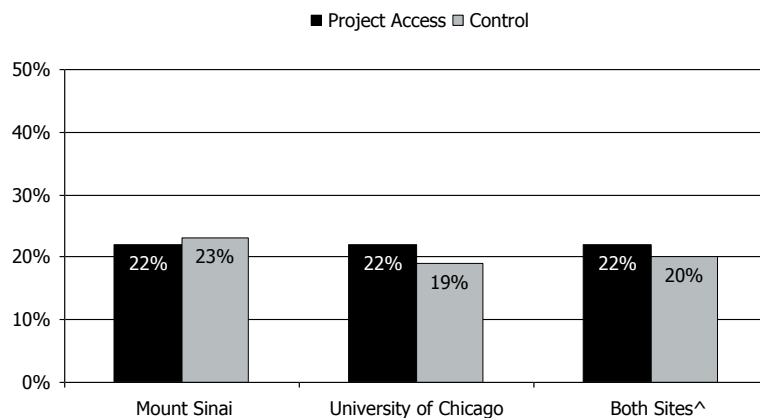
It is less surprising that there are no statistically significant differences among the ability of Project Access and control families to enroll in these programs. All three programs have higher income limits than many other public benefit programs. They also have less demanding reporting requirements, making their benefits easier to retain. For instance, the WIC program makes women eligible for nutrition assistance during their pregnancy meaning that many women begin receiving benefits well before their child is born. The Food Stamp program does not have any job requirements attached to receipt of its benefits if a parent is caring for a dependent child under the age of 6, making it much easier to retain than cash benefits. And finally, all

hospitals complete Medicaid or KidCare applications for their infants born without other medical coverage. Not surprisingly, the hospitals have a strong incentive to ensure that each child is covered and their NICU costs will be paid. As a result, most all infants leave the hospital with medical coverage in place and will remain eligible for KidCare throughout their first year of life.

## 2. PARENTAL COMPLIANCE WITH POST-DISCHARGE CARE

Compliance with care was seen as one obvious benefit or outgrowth of the intensive case management and ongoing relationships established by Project Access. It was also seen as a way to demonstrate increased profit potential for hospitals, since parents utilizing the program were more likely to keep their child's doctors appointments and thereby generate additional revenue for the hospital. Compliance was also thought to show a cost savings to the state by linking infants into a primary care provider instead of using the emergency room (ER) for general care – a much greater expense to the state's Medicaid program. To that end, all patients of the hospitals' high-risk clinics (both intervention and control) received appointment reminder calls by the clinic staff. The on-site meeting time with Project Access case managers and

FIGURE IV.13.  
PERCENT OF MISSED HIGH-RISK CLINIC APPOINTMENTS# FOR PROJECT ACCESS FAMILIES COMPARED TO CONTROL FAMILIES AT 12 MONTHS CGA\*



Source: NICU Infant Outcomes Study (NIOS)

<sup>^</sup> n=153, 103 Project Access, 50 Control

# The missed appointment rate was calculated by taking the total number of missed appointments divided by the total number of scheduled appointments for each group. Appointments that were documented as cancelled either by the family or the clinic were not counted in the total number of scheduled appointments.

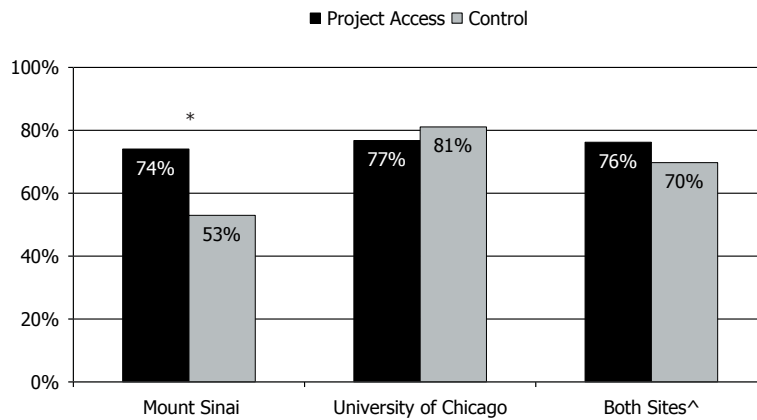
\* None of the statistical comparisons between the Project Access and Control groups demonstrate statistical significance (i.e., none of the p-values are less than 0.05); thus, p-values are not shown.

attorney was seen as an additional incentive for families to attend appointments. Case managers also scheduled both appointments and transportation as needed to make it easier for families to attend follow-up appointments.

To measure compliance with post-discharge care, dates of appointments with high-risk clinic doctors were abstracted from the hospitals' computerized billing systems and/or medical records. A "missed appointment rate" for both the Project Access group

Figure IV.14 presents the percent of Project Access families who were "active patients" in the high-risk clinic at 12 months CGA compared to control families. Project Access families at Mount Sinai were more likely to be active patients at 12 months CGA than control families (74% vs. 53%), but the result was not quite statistically significant (p=0.11). Project Access families at the University of Chicago were no more likely to be active patients than control families (77% vs. 81%, p=0.86).

FIGURE IV.14.  
PERCENT OF PROJECT ACCESS FAMILIES WHO WERE "ACTIVE PATIENTS" IN THE HIGH-RISK CLINIC<sup>#</sup> AT 12 MONTHS CGA COMPARED TO CONTROL FAMILIES<sup>\*</sup>



Source: NICU Infant Outcomes Study (NIOS)

<sup>^</sup> 20 families were excluded from this analysis: 9 families actively withdrew from the study, 7 infants died, and 4 infants entered DCFS custody (n=133, 90 Project Access, 43 Control)

<sup>#</sup> Infants were designated as "active" patients in the clinic if they attended an appointment within 3 months of their 12 month corrected for gestational age (CGA)

<sup>\*</sup> p=0.11. The results are considered statistically significant if the probability of the result (the "p-value") is less than 5% or 0.05. The p-values shown are for statistical comparisons between the Project Access and Control groups.

and the control group was then calculated (see Footnotes in Figure IV.13 for more information). In addition, infants were designated as "active patients" in the clinic if they had an appointment within 3 months of their 12 months corrected for gestational age (CGA).

Figure IV.13 presents the percent of missed high-risk clinic appointments for Project Access families compared to control families at 12 months CGA. Project Access families missed 224 (22%) of 1034 appointments whereas control families missed 101 (20%) of 495. The difference was not statistically significant (p=0.57).

As the data shows, Project Access families were just as likely to miss a high-risk clinic appointment as control families. In fact, the missed appointment rates for the two clinics are similar to published rates for Medicaid patients in a pediatric clinic.<sup>35</sup> However, notably Project Access families at Mount Sinai were more likely to continue to receive ongoing care from the high-risk follow-up clinic throughout their infants' first year.

One explanation for the improvement in the continuity of care at Mount Sinai lies with the Project Access model itself. The project team may have improved the

families' connection to their pediatrician. The team played an integral role in the transition from inpatient to outpatient care at the hospital, establishing an early link with these families. The Project Access families' ongoing connection with the Project Access team facilitated their access to care. In particular they assisted with scheduling appointments and transportation, served as a continuing resource for families on benefit and service issues, and were a source of ongoing support throughout a difficult year. This team approach to service delivery improved the care these families received, which may have reinforced their desire to return for ongoing care. In addition, at Mount Sinai there were no existing resources for non-Project Access families to establish these linkages.

This may explain some of the differences in the appointment compliance data between the two hospitals. University of Chicago has significantly greater resources available to its patient population than Mount Sinai does. The hospital is larger with greater monetary resources. As a result, the high-risk outpatient clinic has a team of people specifically dedicated to scheduling appointments for patients and then calling to remind them. In addition, the clinic staff includes a range of therapists, a nurse educator, nutritionist and social worker, as well as the project case manager who are all available to assist clinic patients and their families. The clinic social worker also provides a reminder call to each family the day before an appointment is scheduled, reinforcing the reminder they receive from the appointment staff. The depth of resources already available at University of Chicago in addition to the project team, may explain why the control families there are equally likely to receive ongoing care as the project families.

In other words, the Project Access model provides systems/methods to ensure continuity of care, but these systems

were already in place at the University of Chicago clinic for both the control and intervention group. However, when Project Access was implemented at Mount Sinai, an institution where those systems were not in place, the percent of patients that continued to receive ongoing care from the high-risk follow-up clinic throughout their infants' first year improved to 74% or close to the same percentage as those for patients at the University of Chicago.

### 3. INFANT HEALTH AND DEVELOPMENT

Infant health and development was seen as the most desirable outcome in which to show substantial improvement; however, it was also recognized as the hardest to impact in such a short time frame. It was theorized that participation in Project Access would ensure a connection to ongoing pediatric care, an essential component of good development. In addition, when developmental delays became apparent or when infants had been referred with no follow-up, the Project Access case managers referred the infant to EI for ongoing therapy services and regularly checked in with families to ensure that eligible infants consistently accessed and received services.

To measure infant development, mother/caregivers completed the Ages and Stages Questionnaire (ASQ) at 4, 8, and 12 months CGA. The ASQ is a parental assessment of their infant's social and motor skills on age appropriate tasks.<sup>36</sup> It has been widely used and validated.<sup>37,38</sup> Examples of questions on the 12 month ASQ are: "Does your baby shake his head when he means 'no' or 'yes'?" and "Does your baby stand up in the middle of the floor by himself and take several steps forward?" Response options are "yes", "sometimes", or "not yet". The ASQ consists of 5 domains: communication, gross motor, fine motor, problem solving, and personal-social. A higher score indicates fuller development.



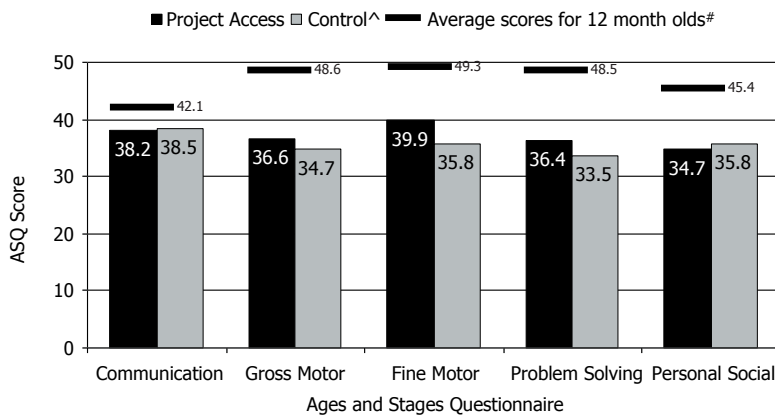


FIGURE IV.15. SCORES FOR EACH DOMAIN OF THE ASQ FOR PROJECT ACCESS FAMILIES COMPARED TO CONTROL FAMILIES AT 12 MONTHS CGA\*

Source: NICU Infant Outcomes Study (NIOS)

^ 41 families are missing this information: 40 were 'Lost to Study' and 1 did not complete the Ages and Stages Questionnaire at their final interview (n=112, 76 Project Access, 36 Control)

# Squires J, et al. *The ASQ User's Guide for the Ages & Stages Questionnaire: A Parent-Completed, Child Monitoring System*, Second Edition, Baltimore, MD: Paul H Brookes Publishing Company, 2001.

\* None of the statistical comparisons between the Project Access and Control groups demonstrate statistical significance (i.e., none of the p-values are less than 0.05); thus, p-values are not shown.

Figure IV.15 presents scores for each domain of the ASQ for Project Access families compared to control families at 12 months CGA. The lines on Figure IV.15 represent the average ASQ scores for a normal pediatric population of 12 month olds. The data show that there are no statistical differences between groups on any of the domains, but that infants in both groups scored significantly lower than the norms (i.e., the 95% confidence intervals for each of the 5 domains did not include the average score for the norms, data not shown).

than the norms, as is consistent with the notion that there is an increased level of need within our study populations (i.e., they are high-risk infants). The data also suggests a higher level of need for EI services for high-risk infants. From our data it appears that Project Access has not shown improvement in this outcome; however, to effectively measure changes in infant health and development, it would require data collection over a much longer time period (i.e., to school age). At the study's outset, the team identified this outcome as the one least likely to be impacted by Project Access services.

In other words, both the Project Access and control groups had ASQ scores lower

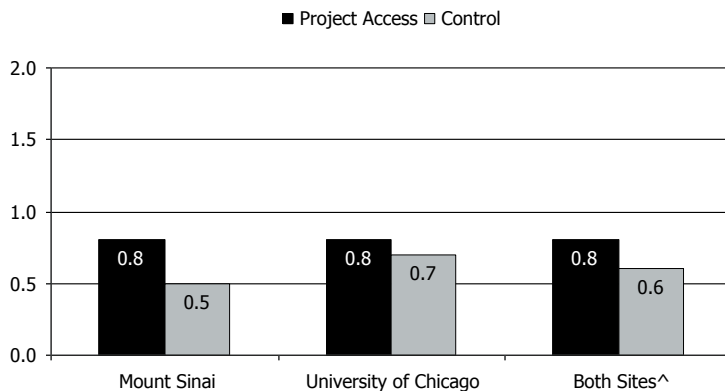


FIGURE IV.16. AVERAGE NUMBER OF RE-HOSPITALIZATIONS FOR PROJECT ACCESS FAMILIES COMPARED TO CONTROL FAMILIES BY 12 MONTHS POST-NICU DISCHARGE\*

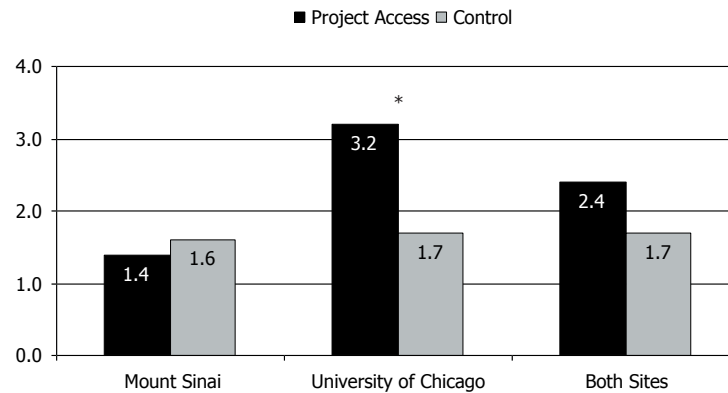
Source: NICU Infant Outcomes Study (NIOS)

^ 56 families are missing this information: 44 were 'Lost to Study' and 12 had incomplete data for one of the four follow-up months - 3, 6, 9, and 12 months post-NICU discharge (n=97, 64 Project Access, 33 Control).

\* None of the statistical comparisons between the Project Access and Control groups demonstrate statistical significance (i.e., none of the p-values are less than 0.05); thus, p-values are not shown.

FIGURE IV.17.

AVERAGE NUMBER OF EMERGENCY ROOM VISITS FOR PROJECT ACCESS FAMILIES COMPARED TO CONTROL FAMILIES BY 12 MONTHS POST-NICU DISCHARGE



Source: NICU Infant Outcomes Study (NIOS)

<sup>^</sup> 56 families are missing this information: 44 were 'Lost to Study' and 12 had incomplete data for one of the four follow-up months - 3, 6, 9, and 12 months post-NICU discharge (n=97, 64 Project Access, 33 Control).

\* p=0.02. The results are considered statistically significant if the probability of the result (the "p-value") is less than 5% or 0.05. The p-values shown are for statistical comparisons between the Project Access and Control groups.

We also looked at emergency room (ER) visits and re-hospitalizations as a measure of the infants' health. Again, it was thought that Project Access activities would ensure the families connection to ongoing pediatric care; and thereby, reduce unnecessary trips to the ER and subsequent re-hospitalizations. To measure ER visits and re-hospitalizations, families were asked every three months post-NICU discharge whether they had taken their infants to the ER and whether the infant had been re-hospitalized. The data in Figure IV.16 and Figure IV.17 are for the 97 families for which there were responses to these questions at every one of the four follow-up months (i.e., 3, 6, 9, and 12 months post-NICU discharge). Data show that overall Project Access families were no more likely to be re-hospitalized (0.8 vs. 0.6, p=0.34) or make ER visits (2.4 vs. 1.7, p=0.15) than control families in the 12 months post-NICU discharge. However, the data reveal that Project Access families at University of Chicago were almost twice as likely to make a trip to the ER than the controls (3.2 vs. 1.7, p=0.02).

Again, infant health was seen as the outcome least likely to be effected by the Project Access intervention in such a short time period. The fact that the average number of re-hospitalizations and

ER visits was similar for project infants as the controls confirms this. The increased number of ER visits among Project Access infants at University of Chicago is likely due to the inappropriateness of using ER visits as a measure of infant health and/or compliance with the infants' medical plan. Both clinics operate only part time; thus, their pediatricians often referred their patients to the ER when the infant needed medical care on a day the clinic was closed. More will be said on this in the report's Lessons Learned section.

#### 4. MATERNAL/INFANT QUALITY OF LIFE

Parental stress is common after the birth of any child and almost a certainty when that child is low birthweight or born with other serious medical complications. In an effort to provide comprehensive or holistic services to Project Access families, supportive counseling was one of the interventions provided to project families. In fact, 88% of Project Access families received supportive counseling from their Project Access case manager and counseling referrals were made for those mothers who needed ongoing or more in depth mental health services. Additionally, the multi-disciplinary approach of Project Access allowed the team to "holistically" address any problems as they arose.

Maternal/infant quality of life was measured by the use of two psychometric instruments administered by the NIOS research assistant at 4 and 12 months CGA: 1) the short form of the Parenting Stress Index (PSI-SF) and 2) the Impact of Chronic Illness on a Family Scale. Both are discussed below.

*Parenting Stress Index (PSI-SF)*

The PSI-SF is a frequently used instrument designed to assess parents' feelings regarding their role as a parent. The PSI-SF yields a Total Stress score, which indicates the overall level of stress experienced by the parent as a result of their parenting role.<sup>39</sup> Examples of questions on the PSI-SF are: "I feel trapped by my responsibilities as a parent" and "My child turned out to be more of a problem than I expected." Each of the questions are rated on a 5-point Likert scale ranging from 1—"strongly disagree" to 5—"strongly agree." A higher Total Stress score indicates greater parenting stress.

*Impact of Chronic Illness on a Family Scale*

The Impact of Chronic Illness on a Family Scale measures the effect of the infant's illness on the family system. This impact can be felt financially (e.g., changes in the economic status of the family),

socially (e.g., the quality and quantity of interaction with others both within the family and outside of the family), and personally (e.g., subjective burden experienced by the primary caretaker and/or feelings of mastery and coping).<sup>40</sup> Questions on the scale include:

- "Time is lost from work because of hospital appointments";
- "We see family and friends less because of the illness";
- "Learning to manage my child's illness has made me feel better about myself".

Each question is rated on a four-point Likert scale ranging from 1—"strongly agree" to 4—"strongly disagree." Responses are combined such that a higher score indicates more impact on the family (a negative dynamic).

Figure IV.18 presents the parenting stress experienced by Project Access families at 12 months CGA compared to control families. The line on Figure IV.18 represents the parenting stress of parents of children aged 10-84 months from a normal pediatric population. The data show that, overall, parents in both the Project Access and control groups experience similar parenting stress to that of the norms. However,

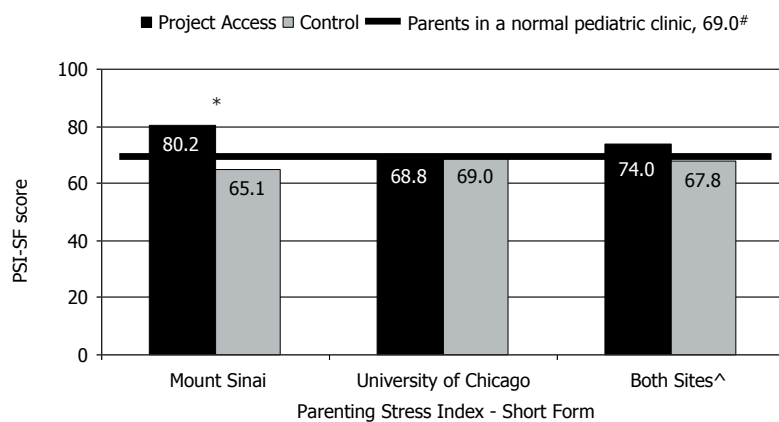
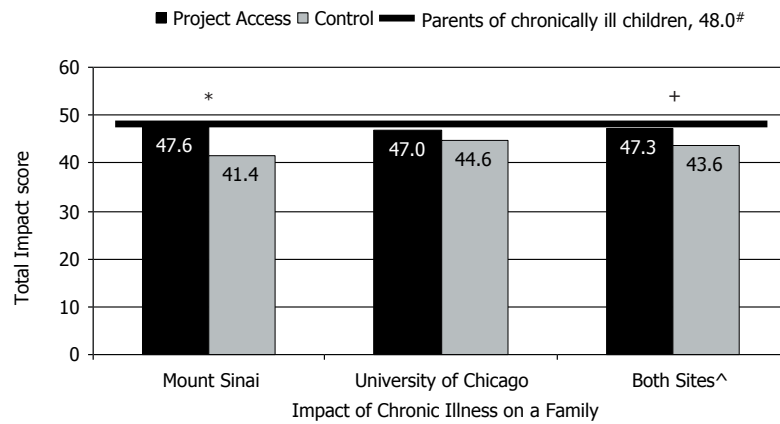


FIGURE IV.18. PARENTING STRESS EXPERIENCED BY PROJECT ACCESS FAMILIES AT 12 MONTHS CGA COMPARED TO CONTROL FAMILIES

Source: NICU Infant Outcomes Study (NIOS)

^ 44 families are missing this information: 41 were 'Lost to Study' and 3 did not complete the PSI-SF at their final interview (n=109 73 Project Access, 36 Control)  
 # Abidin RR. *Parenting Stress Index*, Third Edition, Lutz, FL: PAR Psychological Assessment Resources, Inc., 1995.  
 \* p=0.03. The results are considered statistically significant if the probability of the result (the "p-value") is less than 5% or 0.05. The p-values shown are for statistical comparisons between the Project Access and Control groups.

FIGURE IV.19.  
‘IMPACT OF CHRONIC  
ILLNESS ON A FAMILY’  
FOR PROJECT ACCESS  
FAMILIES AT 12 MONTHS  
CGA COMPARED TO  
CONTROL FAMILIES



Source: NICU Infant Outcomes Study (NIOS)

<sup>^</sup> 45 families are missing this information: 41 were 'Lost to Study', 3 did not complete the instrument at their final interview, and 1 skipped several questions - too many to accurately score the Total Impact (n=108, 73 Project Access, 35 Control)  
# Stein RK and Jessop DJ. *Tables Documenting the Psychometric Properties of a Measure of the Impact of Chronic Illness on a Family*, Bronx, NY: Albert Einstein College of Medicine of Yeshiva University, 1985.  
\* p=0.07. The results are considered statistically significant if the probability of the result (the "p-value") is less than 5% or 0.05. The p-values shown are for statistical comparisons between the Project Access and Control groups.  
+ p=0.05

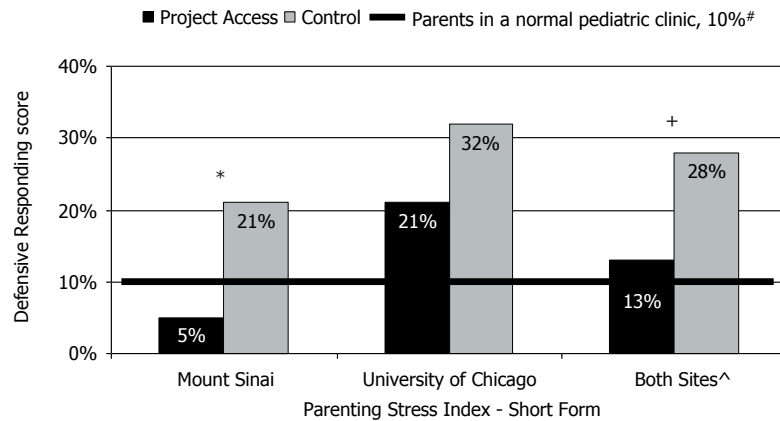
Project Access mothers at Month Sinai experienced significantly higher levels of stress than control mothers (80.2 vs. 65.1 respectively, p=0.03).

Project Access mothers experienced higher levels of impact than control mothers (47.3 vs. 43.6). This difference was statistically significant (p=0.05).

Figure IV.19 presents the ‘Impact of Chronic Illness on a Family’ for Project Access families at 12 months CGA compared to control families. Here, the line represents the average ‘total impact’ score for a sample of parents of chronically ill children. Again, the data reveal that parents in both NIOS groups experienced similar levels of impact as that of parents of chronically ill children; but overall,

It appears from our data that higher maternal stress/impact (i.e., poorer maternal/infant quality of life) was identified in Project Access families. This is a somewhat surprising result as the evaluation expected to find improved quality of life in Project Access families. One explanation of the higher stress/impact scores is that the case managers provided supportive counseling to

FIGURE IV.20.  
DEFENSIVE RESPONDING  
SCALE AT 4 MONTHS CGA  
FOR PROJECT ACCESS  
FAMILIES AS COMPARED TO  
CONTROL FAMILIES



Source: NICU Infant Outcomes Study (NIOS)

<sup>^</sup> 24 families are missing this information: 22 were 'Lost to Study' and 2 did not complete the PSI-SF at the 4 month CGA interview (n=129, 90 Project Access, 39 Control)  
# Abidin RR. *Parenting Stress Index*, Third Edition, Lutz, FL: PAR Psychological Assessment Resources, Inc., 1995.  
\* p=0.09. The results are considered statistically significant if the probability of the result (the "p-value") is less than 5% or 0.05. The p-values shown are for statistical comparisons between the Project Access and Control groups.  
+ p=0.04

most of the Project Access families and through this supportive counseling, families became more aware of the stress they experienced; and, thus, reported more stress/impact. In addition, many of the questions on the PSI-SF and Impact of Chronic Illness on a Family Scale were extremely sensitive. For example the PSI-SF asks, “My child rarely does things for me that make me feel good” and “I feel trapped in my responsibilities as a parent” – questions whose answers could suggest abuse. It is possible that Project Access families felt more comfortable disclosing sensitive information to the research assistant because of the trust established between the Project Access case manager and family. This would allow them to respond more openly to questions which revealed that they were suffering from higher stress/impact. Control families, on the other hand, may not have answered as candidly and instead may have chosen a more socially desirable response; therefore, they were not as likely to have high stress/impact scores.

We see some evidence of this in the PSI-SF scores at 4 months CGA. The PSI-SF also includes also a Defensive Responding scale that assessed the extent to which the respondent approaches the questionnaire with a strong bias to present a favorable impression and is minimizing their problems/stress. Scores of 10 or below on the Defensive Responding scale suggest that the respondent may not be willing to acknowledge the pressures, frustrations, and annoyances of parenting she is experiencing.<sup>41</sup> Figure IV.20 presents the Defensive Responding scale at 4 months CGA for Project Access families as compared to control families. Control families were twice as likely to respond defensively on the PSI-SF as compared to Project Access families (28% vs. 13%, respectively) and the difference was statistically significant ( $p=0.04$ ). However, at 12 months CGA, the difference in defensive responding between controls and Project Access families was not as striking (12% vs. 19%,  $p=0.32$ ).

Overall, 58 mothers/caregivers (44%) were identified as suffering from high parenting stress (i.e., had PSI-SF score greater than the 90<sup>th</sup> percentile as compared to the norms) by the NIOS research assistants at either the 4 or 12 month CGA interviews. Whenever high stress levels were identified in either Project Access or control families, members of the team worked with the family to address the issue. In other words, using the PSI-SF as a screening tool was useful for all participating families. More will be said on this in the section Lessons Learned.

#### D. OTHER OUTCOMES

In addition to impacting the outcomes measured specifically through the NIOS research study, Project Access also led to positive outcomes in other areas affecting the target population. In particular, Project Access led to significant advocacy efforts for systems change within programs relevant to these families and it also contributed to the development of a “medical home” at each participating hospital site.

##### 1. SYSTEMIC ADVOCACY SUCCESSES

Throughout the project’s four years of operation, the team experienced numerous advocacy successes within the different public benefit and social service programs that Project Access targeted. Through the team’s work with individual clients, they identified specific problems in individual situations. They then used these experiences to inform larger advocacy issues and work directly with the relevant agencies to effect change.

##### *Social Security Administration*

Some of Project Access’ greatest advocacy accomplishments came from the team’s relationship with the Social Security Administration (SSA). Because most of Project Access infants are presumptively eligible for Supplemental Security Income

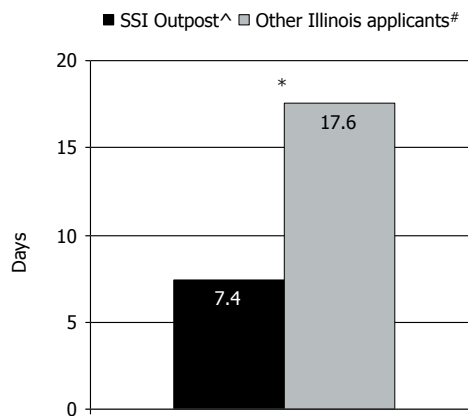
or SSI benefits, the team recognized this as an opportunity to improve the system for participating families. Using their existing relationships with SSA staff, the project Access team streamlined the application process for these infants, reducing the amount of medical paperwork required to process these claims to one single sheet of paper that listed the infant's birthweight and gestational age. Once signed by a doctor, this form was all that was required to substantiate the medical case on an SSI application for a low birthweight infant, thus eliminating the need for any further medical development to be done on the claim.

Initially these forms were faxed to a designated person at one of the SSA local offices who would then schedule an appointment for the family to come in to the office and process the application.

to apply for benefits for their low birthweight or otherwise medically complicated infants right in the hospital's NICU. This prevented families from having to make multiple trips into their local SSA office, and often allowed them to begin receiving benefits before their infant was discharged from the hospital.

Through the good relationships that the Project Access team has established with SSA, we have been able to track the benefits of the project's streamlined application process. The Bureau of Disability Determination Services (BDDS), the organization responsible for making disability determinations on SSI cases, has been tracking the Project Access low birthweight applications since the project started. As a result, we were able to compare the medical decision processing times for Project Access low birthweight

FIGURE IV.21.  
AVERAGE NUMBER OF DAYS BEFORE A DISABILITY DETERMINATION WAS MADE ON THE LOW BIRTH WEIGHT SSI APPLICATIONS IN ILLINOIS



Source: Bureau of Disability Determination Services (BDDS)  
<sup>^</sup> Project Access low birth weight applications processed thru the SSI Outpost at the University of Chicago, September 01, 2003 to August 20, 2004, n=36  
<sup>#</sup> All other low birth weight applications in Illinois, n=632  
 \* p<0.001. The results are considered statistically significant if the probability of the result (the "p-value") is less than 5% or 0.05.

After the team's initial success with SSA in advocating for low birthweight infants, they began looking for a way to further streamline the process for these families and began working to establish an SSA outpost at one of the Project Access sites, the University of Chicago Children's Hospital. Within a few months, the team had an agreement from SSA representatives to come on-site, a few times each month, to both hospitals and complete SSI applications, enabling families

infants to all other low birthweight SSI applications in Illinois. Figure IV.21 shows the average number of days before a disability determination was made on the low birthweight SSI applications. The results show that the non-'Project Access' cases took twice as long for a medical decision as compared to Project Access cases (18 days vs. 7 days) and this difference was highly significant (p<0.001). In addition, the range of days it took to

process these cases was 1 – 259 days, whereas the Project Access case processing times ranged from only 3 – 14 days.

This streamlined system subsequently reduced the processing time on these cases from an average of 90 – 120 days down to as short as two weeks. Once SSA recognized the success of this model within the Project Access hospitals, the agency sent out a national memo to local offices encouraging them to use the Project Access system for SSI applications on low birthweight infants.

While it is obvious that this improved application processing system is beneficial to the families of low birthweight infants, it is important to point out that it is actually beneficial to all parties involved. The hospitals are now able to provide a valuable service to their patients – it is just one more way that they can assist their surrounding communities. In addition, it simplifies the medical reporting requirements for these infants thus saving physicians and other healthcare professionals valuable time by not having to complete extensive SSA paperwork to document the medical situations of these infants.

SSA has also benefited from this streamlined system. Establishing these hospital outposts has provided the participating local offices with a valuable community outreach opportunity. In addition, it is a more efficient means of processing these applications. By minimizing the amount of paperwork that needs to be completed and the medical records that must be obtained, the Project Access method saves SSA both time and resources on all low birthweight applications completed this way. As a result of this success, the local offices have agreed to continue coming onsite to both hospitals each month to continue taking SSI applications even now that Project Access is complete. This long-term commitment is a tribute to the strong relationship formed between the hospitals and the SSA local offices.

### *Department of Human Services*

Another area where the team experienced significant success in systemic advocacy was in a specific problem they discovered in the public aid policy on enrollment in the KidCare program. During their work with participating families, the case managers and attorney began to notice that a number of the project infants had been put on a Medicaid plan with a high monthly spenddown amount, similar to an insurance deductible, even though the infants were eligible for medical coverage under one of the state's KidCare plans which provides full medical benefits with no monthly spenddown. The common denominator within these families was employment income that had increased within the last six months. This income increase put them above the income limits for regular Medicaid, but was still low enough to qualify them for one of the KidCare programs. At the time their medical case came up for redetermination, their public aid worker recorded the income increase but left the child on Medicaid – with a large monthly spenddown amount – rather than switching their case to the appropriate KidCare plan that they were eligible for.

When project staff noticed this happening, they researched the rules and found that the Illinois Department of Public Aid's policy on how local offices should deal with this situation was vague. The project team then began advocating with Public Aid administrators and the Department agreed that this problem needed correction. As a result, they agreed to rewrite the existing policy on this issue and also agreed to re-train their staff to avoid this situation in the future. In addition, the Department also agreed to search their current client caseload to identify other Medicaid recipients who may be experiencing this problem and switch them to an appropriate KidCare plan.

Project Access also uncovered another common problem that exists for families receiving Medicaid for their high-risk infants. Throughout the course of the program, it became clear that participating families were repeatedly being enrolled into Medicaid HMOs. This presents a large problem for high-risk infants who generally need medical follow up with a range of specialists who they are unable to see once they are enrolled in an HMO. Frequently, families are approached at a supermarket or in a shopping center parking lot and are offered a program that will provide them with free diapers and transportation to their children's medical appointments. What they typically do not understand is that signing up to receive these free services also enrolls them into an HMO which may prevent them from taking their children to see their current physicians. Families are not aware that they have changed their insurance coverage until they bring their child in to see their pediatrician and are turned away at the front desk because they are now part of an HMO that the hospital will not accept. Once the child is enrolled in the HMO, it takes more than a month to have them switched back to a regular Medicaid plan. This is extremely problematic for these high-risk infants who require frequent follow-up care from numerous physicians. Any lapses in their care can be dangerous for the infants' long-term prognosis. After becoming aware of this problem, the team began meeting with hospital administrators, HMO administrators and the Department of Public Aid to ensure that this practice does not continue in the future.

In addition to the team's work on changing Medicaid HMO enrollment practices, they also worked to improve the Medicaid transportation system. Early on in their work with Project Access families, it became clear that these families were having great difficulty accessing the Medicaid transportation system to take them to and from their children's medical appointments. Oftentimes families would

be unable to schedule transportation for medical appointments because they were never able to get anyone to answer their calls at the transportation hotline. In other situations, families would schedule transportation to one of their child's appointments then miss that appointment because the transportation never arrived to pick them up. Because the project families were experiencing so many problems accessing transportation through Medicaid, the project team began working with the Department of Public Aid to correct these problems. Consequently, the Department has made significant improvements to the transportation system, which has subsequently improved over time.

## 2. DEVELOPMENT OF THE MEDICAL HOME

In addition to Project Access' significant systemic advocacy accomplishments, some of its greatest impact can be seen within the infrastructure and function of the hospital clinics. The project's multi-disciplinary service delivery model contributed to the development of the medical home at each of the hospital sites. A medical home is a proactive service provision system based on the successful partnership of pediatric health care professionals and non-medical professionals working together to identify and access the range of medical and non-medical services available to help address the entire family's situation, not just the specific medical needs of the child. It emphasizes convenience for the family, allowing them to access various services within the medical care setting rather than trying to navigate their way through a range of disparate systems.

In addition to the added services it provides, the medical home also increases families' connections to their child's primary care provider. This linkage is especially important for families experiencing the dangerous combination of extreme socioeconomic need and caring for a high-risk, medically complex



infant. With the amount of intensive medical treatment required throughout these infants' first year of life, a strong relationship with the child's pediatrician becomes essential and the medical home facilitates that relationship.

Although many of their patients rely on public benefits programs for their medical care and living expenses, physicians are given no formal introduction to social services or public benefits. Once they begin practicing medicine they are confronted with these programs as their patients encounter problems accessing them but have little knowledge of how to be effective advocates for their patients. Physicians neither have the time nor staff resources to negotiate the complicated public benefits systems on behalf of patients.

The medical home created through the Project Access medical-legal-case management collaborative has provided the team's physicians with a more effective and efficient method of advocacy within these complex social service systems. The Project Access model reached across professional boundaries and integrated social factors into medical care, enabling its physicians to provide more socially and culturally competent health care, which is especially important in treating extremely high-risk infants.

## V. Lessons Learned

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AS IS EVIDENT FROM THE OUTCOMES DISCUSSION ABOVE, the project's four years of service delivery have revealed valuable information about this population and their experiences caring for high-risk infants. In addition to the outcomes specifically measured by the study, the team has learned several valuable lessons through their data collection and individual client experiences.

### 1. PROJECT ACCESS FAMILIES DEMONSTRATED A GREATER LEVEL OF ECONOMIC AND EMOTIONAL NEED THAN ANTICIPATED

Project Access was developed to provide assistance to a population that was known to have a high level of social support needs. However, from the beginning of the team's data collection, it was apparent that the project staff had actually underestimated the level of need within these families, both socio-economically and emotionally.

The research assistants' personal experiences interviewing participating mothers confirm the high need and isolation of project participants. In several instances, they reported finding that the project mothers used their data collection interviews as an outlet to talk about their lives, their plans and their frustrations. Both research assistants reported numerous incidents where they learned of significant problems a study participant was facing while conducting an interview. Oftentimes, they considered the problems to be so severe that they subsequently contacted a case manager, attorney, pediatrician or other health care provider so that the families' issues would be addressed. In fact, 44% of participating mothers were identified as "experiencing high levels of parenting stress" by using the PSI-SF (>90%tile). Because the research assistant's became aware of their high stress levels, they

were able to refer them to the child's pediatrician for further evaluation and follow-up.

### 2. THE SITE OF THE INTERVENTION MATTERED

While the same basic program structure was put in place at both project sites, the variations in both size and structure at both hospitals contributed to significant differences in how the project operated at the two participating institutions. The University of Chicago is a much larger institution, with greater resources than Mount Sinai, which is a smaller hospital with very limited resources. Prior to Project Access, the clinic at the University of Chicago already had an existing staff which included a range of healthcare professionals such as: a doctor; nutritionist; nurse educator; and several different types of therapists. At Mount Sinai, the pediatrician was the only pre-existing clinic resource. Therefore, the depth of resources available at the University of Chicago may have diminished their visible results from the Project Access intervention.

### 3. PARTICIPATION IN THE STUDY BENEFITED BOTH THE INTERVENTION & CONTROL GROUPS

As mentioned before, both research assistants reported that that the project mothers used their data collection interviews as an outlet to talk about their lives, their plans and their frustrations. In fact, during data collection interviews various project participants asked research assistants if they were a case manager. Others referred to the researchers as their "counselors." During their participation in the study, the researchers often met with these mothers six or seven times in person for anywhere from 15 to 90 minutes. This suggests that many of the project's mothers valued

the time they spent with the research assistants, independent of their individual contributions to the study. Simply having the opportunity to talk about their problems seems to have been therapeutic for many of them and in fact, these interviews may have been one of the few emotional outlets that these mothers had—in both the control group and the project participant group. As mentioned earlier, any time that the research assistants became aware of a serious problem that participating families needed to have addressed, they would speak with doctors or other relevant professionals working with these families to get them the help they required. This alone was a valuable resource to both participants and professionals who might not have been aware of these situations without the research assistants' information.

In addition to the emotional support research assistants offered through the time spent with project participants, the very existence of the project and the presence of the team members in the clinics provided the healthcare professionals and other hospital staff with access to a range of information they would not have otherwise been aware of. The case managers and attorney were public benefits experts who provided information on relevant benefits and services and answered questions for clinic staff on a range of issues that arose at the hospitals' clinics. To this end, they were seen as resources in the clinic and were inevitably asked for information, advice and counsel by the general clinic staff.

#### 4. USEFULNESS OF OUTCOMES MEASURED

After four years of project operation, the study's data set is very rich. The team collected information on multiple aspects of the participants' lives, their experiences caring for high-risk infants and their ability to access the necessary benefits and services. Not surprisingly, some of the outcomes measured elicited more useful information than others.

For example, the study collected information on Emergency Room visits and re-hospitalizations after NICU discharge. However, because both participating hospitals have part-time clinics, their pediatricians often advised parents to take their children to the ER if they called needing medical care on a day that the clinic was not open. As a result, an ER visit may in fact have indicated that a family was being compliant with their child's medical care plan. This trend may be reflected in the study's data, which shows that the Project Access families at University of Chicago actually made an average of 3.1 visits to the ER whereas control families only made an average of 1.7 visits to the ER ( $p=0.02$ ).

The study also collected data on the growth and development of participating infants. The project was designed so that the team only followed infants from their birth until they reached one year corrected age. Because this is a relatively short time period over the course of their lives, it was difficult to demonstrate significant differences in infant growth and development. The study's results showed no overall difference between the Project Access and control groups at either hospital. Therefore, measuring infant growth and development would have been better suited to a study that followed infants for a longer time period, perhaps through the time they reached school age.

#### 5. THE STUDY IDENTIFIED ADDITIONAL PROGRAM AREAS FOR ADVOCACY

The data collected through Project Access provided a range of information on the targeted programs and services. Through this data, additional areas for advocacy became apparent. One program in particular where the study's data has shown additional opportunity for advocacy is within the Early Intervention (EI) program.

The participation rates in the EI program were low among all study participants, particularly in their first 6 months post-NICU discharge. At that point, only 60% of all likely eligible infants were receiving EI services. These results suggest that the Project Access intervention was not particularly successful in increasing EI participation rates.

Several variables were associated with early participation among families: referring provider, maternal education level, and any observable delays in the infant. In fact, only 30% of those not receiving EI services thought that their infant needed these services, suggesting that many of these families did not recognize the value of these services for their infants.

As a result of the data uncovered by the study, the project team began working with the EI service providers to share this information and develop ways to improve families' access to the EI program. The University of Chicago team has begun meeting with the EI director serving their catchment area and has already developed a plan to increase earlier referral to and enrollment in the system. As part of that plan, an EI liaison now comes to clinic twice a month to help facilitate EI service issues and answer questions. So far, she has assisted families in resolving disruptions in their services. She has met with families who needed to update EI with new addresses or contact information, and she has helped set up EI services in a timely fashion when clinic staff discover a child's delay during a routine clinic visit. In the past, these issues could not have been resolved without the family experiencing some interruption in their child's services. This improved system has help to minimize those interruptions and has the potential to decrease the time eligible infants are waiting to begin receiving EI services.

The team hopes that disseminating this information to a range of other

providers will help facilitate additional improvements in the EI system. The research team is working on a journal article to disseminate this information more broadly, as we are unaware of other studies looking at factors impacting EI participation rates.

## 6. EXISTING NEED FOR ONGOING TECHNICAL ASSISTANCE

The Project Access model was successfully implemented at two hospital sites and the work done at each site generated interest from other hospital medical staff that were interested in having access to the information and resources that the project provided. In addition, in some of the national push to reform residency training programs, there are increasing opportunities to provide education and training to medical professionals on public benefits issues. This suggests that there is an existing opportunity for education and training among medical professionals and other hospital staff. Health & Disability Advocates has already started addressing some of this need through its Technical Assistance Project where they are developing resources for hospital social workers on a range of public benefits programs. The national interest Project Access has generated has also created a demand for technical assistance to other organizations interested in trying to develop medical-legal collaborations. The project team is exploring possible relationships with other leading medical-legal collaborations nationally to promote replication of these models.

## LESSONS LEARNED FROM OTHER SOURCES

### 1. PROJECT ACCESS PRESENTS A WIDE RANGE OF RESEARCH AND PROGRAMMING OPPORTUNITIES

Included in the appendix to this document is a list of presentations that the Project Access team has made at various conferences and national

meetings over the last few years of project operation. It is evident from this extensive list of research accepted for presentation, that the model has been extremely well received among a variety of professionals. This further emphasizes the utility and versatility of the research. It also suggests that there is a range of future research and programming opportunities available from the strong foundation created by this pilot project. In addition, the team is determined to disseminate the study's results and is working on several different concepts for papers to submit to various journals describing different pieces of the model and its research.

## 2. PARTNERSHIP OPPORTUNITIES WITH OTHER MEDICAL-LEGAL COLLABORATIONS

As mentioned earlier, the novelty of this model and specifically its evaluation component has generated interest from other medical-legal collaborations nationally. This will likely lead to opportunities for partnership with these other national organizations in the future and in fact, as mentioned earlier, the team has already begun talking with other medical-legal collaborations about developing a technical assistance model to promote the development of these types of service delivery systems.

### THE FOUR-YEAR PROJECT ACCESS DEMONSTRATION ended in 2004.

Participants in the program have had many discussions about how to continue key elements of the intervention, including: What essential components of the program do the participating institutions hope to keep in place, even when funding resources are limited?

The Project Access Team considered and evaluated three main models for program continuation. These three options are viewed as possibilities not only for the Chicago-based Project Access team, but also for agencies and hospitals in other areas of the country. Each of the three models has strengths and weaknesses, and determining which model will work most effectively requires a careful community needs and resource assessment.

#### MODEL 1 – PROJECT ACCESS REPLICATION

This model contemplates a service delivery model similar to the one pioneered by the Project Access team at the University of Chicago Children's Hospital and Mount Sinai Children's Hospital. Program services would include intensive case management and free legal services, offered on-site at hospital NICUs and at outpatient follow-up clinics to families of medically fragile infants. Program services are provided by a part-time or full-time case manager who is a hospital employee (either from the social work team or nursing staff), and part-time or full-time attorney services from an agency such as Health & Disability Advocates, working in close connection with the hospital's medical team.

#### MODEL 2 – TECHNICAL ASSISTANCE

Under the Technical Assistance Project model, an independent legal services provider agrees to work with one or several outpatient and inpatient medical

facilities to provide training, technical assistance, resource guides and materials, for medical providers, social workers and case managers, in the areas of public benefits and healthcare access. The legal service provider's role can also include provision of back-up legal services to patient families who need help accessing or retaining public benefits, health care insurance or medical/developmental/therapeutic services. However, the primary focus is on training the physicians, case managers and social workers to identify public benefits issues, make appropriate referrals and provide minimal administrative advocacy. This Technical Assistance Project is less expensive than a multi-institution, heavily staffed program such as Project Access. Essentially, the legal services provider finds salary support for its own attorney, but also asks for hospital buy-in – space, materials, time for staff to attend trainings, etc. This model also has a great deal of flexibility in terms of how a partnership with the hospitals is arranged. However, the Technical Assistance Project model has the potential downside of losing the key long-term relationships between patients and case managers that were at the core of the Project Access intervention.

#### MODEL 3 – FAMILY-ADVOCACY PROJECT, MEDICAL-LEGAL COLLABORATION MODEL

Based on the Family Advocacy Project model, pioneered by the Boston Medical Center, the medical-legal collaboration involves placing an attorney on-site at an outpatient pediatric clinic associated with a local hospital. Taking referrals from medical providers, the onsite attorney assists families with a range of general civil legal services, including housing conditions, public benefits, insurance issues, and school advocacy issues. Hospital medical and social service staff receive advocacy training, learn how to spot legal issues, and make appropriate referrals to the onsite attorney. The attorney can either be a hospital employee

or a legal services attorney who uses hospital space to conduct client intake and provide legal counsel.

While it is beyond the scope of this report to discuss all the advantages and disadvantages of the three models, Health & Disability Advocates of Chicago welcomes inquiries about any of these three models, and, upon request, will share additional information about the potential strengths and weaknesses of each model. HDA also recommends the Boston Medical Center as an excellent resource for learning more about a range of medical and legal collaborations that are underway across the country.

PROJECT ACCESS began in the Spring of 2000 when a group of Chicago-based doctors, social workers, lawyers and hospital administrators met with representatives from the Michael Reese Health Trust and posed the question “How can we improve services and social supports for high-risk infants and their families?”

What emerged from those early planning sessions was a new model of care – one that emphasized not only providing top quality medical services to meet the intensive medical needs of the high-risk neonate, but also offering a range of case management and legal services to address the often under-reported and over-looked social and economic needs of the family.

In this summary report of Project Access and the NICU Infant Outcomes Study, we have discussed the program’s strengths and weaknesses, its impact and results on both the individual and systemic levels, the valuable lessons learned

from the program implementation, and recommendations for future program development and study. We believe that the successes documented in this report make a compelling case for continuation of collaborative interventions. All those involved with this project – from the neonatologists and nurses to the social workers and lawyers – believe that they became more effective providers and advocates when they worked together, and most importantly, that family supports improved as a result. This shared belief among the providers was also born out by client testimonials and by carefully documented research findings. Project Access has demonstrated that the benefits of cross-disciplinary care inure to high-risk infants and their families, whose needs are more likely to be fully assessed and appropriately and expeditiously addressed in the context of a collaborative, cross-disciplinary “medical home.”

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## Appendices

### APPENDIX A. KEY PROJECT ACCESS TEAM MEMBERS AND THEIR ROLES IN THE PROGRAM

PROJECT ACCESS POSITION TITLE	NAME	QUALIFICATIONS	EMPLOYING AGENCY	JOB DESCRIPTION
Project Access Director	Julie Justicz	JD	Health & Disability Advocates	Oversaw program design and implementation; advanced overall goals of the program; convened and chaired meetings of the Steering Committee; and managed and accounted for the appropriate expenditure of program funds.
Project Access Staff Attorney	Laura Barnickol	JD/MSW	Health & Disability Advocates	Provided legal advice, counseling and representation to Project Access families on a range of civil legal matters; conducted public benefits education and provided coaching and support to case managers; and conducted administrative advocacy to challenge systemic barriers.
Project Access Case Manager	Elaine Mister	RN	University of Chicago Children's Hospital	Provided resource referrals, coordination of care, benefits referral and application assistance, supportive counseling, and education on public benefits and services to Project Access families.
Project Access Case Manager	Minerva Esparza	MSW	Mount Sinai Children's Hospital	Provided resource referrals, coordination of care, benefits referral and application assistance, supportive counseling, and education on public benefits and services to Project Access families.
Project Access Hospital Program Director	Maria Corpuz	MA	University of Chicago Children's Hospital	The project director at each participating hospital had direct responsibility for ensuring that the hospital met its responsibilities in carrying out the program and did all it could to ensure that the overall objectives of the program were achieved.
Project Access Program Director	Edith Njuguna		Mount Sinai Children's Hospital	The project director at each participating hospital had direct responsibility for ensuring that the hospital met its responsibilities in carrying out the program and did all it could to ensure that the overall objectives of the program were achieved.
Principal Investigator and Neonatologist	Dr. Gopal Srinivasan	MD	Mount Sinai Children's Hospital	Provided direct medical care to high-risk NICU graduates in Mount Sinai Hospital's follow-up care clinic. Responsible for follow-up medical care of all Project Access infants enrolled at Mount Sinai. Oversaw medical elements of Project Access study at Mount Sinai; Principal Investigator on research study.
Principal Investigator and Neonatologist	Dr. Jaideep Singh	MD	University of Chicago Children's Hospital	Neonatologist in NICU; provided medical care to high-risk infants admitted to NICU. Oversaw medical elements of Project Access study at U of C; Principal Investigator on research study.

PROJECT ACCESS POSITION TITLE	NAME	QUALIFICATIONS	EMPLOYING AGENCY	JOB DESCRIPTION
Pediatrician/ Follow-Up Clinic	Dr. Rupa Nimmagadda	MD	University of Chicago Children's Hospital	Pediatrician at high-risk follow-up clinic at U of C. Responsible for follow-up medical care of all Project Access infants seen at U of C.
Research Fellow	Dr. Janell Fuller	MD	University of Chicago Children's Hospital	Neonatology Fellow. Provided vital assistance to medical elements of Project Access; intricately involved in Project Access research study.
NIOS Evaluation Coordinator	Jocelyn Hirschman	MPH	Sinai Urban Health Institute	Oversaw research design and implementation; advanced overall goals of the research project; supervised research assistants; convened and chaired meetings of the Research Team; managed and accounted for the appropriate expenditure of research funds; analyzed research data.
Research Assistant	Sheena Freeman		Sinai Urban Health Institute	Conducted data collection, data entry and data analysis under the guidance of the Evaluation Coordinator.
Research Assistant	Grace Lee		University of Chicago Children's Hospital	Conducted data collection, data entry and data analysis under the guidance of the Evaluation Coordinator.

APPENDIX B. TIMETABLE FOR DATA COLLECTION

The table below summarizes the family’s involvement with NIOS research study. The steps indicated in gray are for the Project Access intervention families only.

DATE	LOCATION†	TYPE OF INTERACTION	STAFF INVOLVED	TIME OF INTERACTION WITH FAMILY
1-2 days after admission	NICU	Completion of Screening Form	Case Manager	0-10 minutes
3-4 weeks before discharge	NICU	Overview of NIOS, Review/ Discussion of Protocol/, Completion of Informed Consent/ Authorization to Communicate forms, Intake/ Locator forms	Case Manager	2 hours
3-4 weeks before discharge	NICU	Overview of NIOS/ Protocol, Completion of Demographics survey/ Social Services Survey – Month 0/ Housing/ CRISYS/ MHLC/ Social Support Survey/ and SF-36	Research Assistant	1 hour
3-4 weeks before discharge	NICU	Project Access Intake Form Discussion of Family Concerns and Needs	Case Manager	30 minutes
1 week before discharge or 1 <sup>st</sup> clinic visit	NICU/ Clinic	Review Family Service Plan	Case Manager/ Attorney	60-90 minutes
At discharge	NICU	Family Discharge Planning Conference w/ neonatology staff	Case Manager	30-60 minutes
At least every 3 months post-discharge	Clinic	Follow-up Meeting with Family	Case Manager and/or Attorney	30 minutes
3 months post-discharge	Clinic	Overview of NIOS/ Protocol, Completion of the Unscheduled Use Medical Facilities/ HRQOL/ Social Services Survey – Month 3	Research Assistant	25 minutes
4 months corrected age	Mail	Overview of NIOS/ Protocol, Completion of PSI/ Impact on Family/ Ages and Stages Questionnaire	Research Assistant	30 minutes
6 months post-discharge	Clinic	Overview of NIOS/ Protocol, Completion of the Unscheduled Use Medical Facilities/ HRQOL/ Social Services Survey – Month 6/ CRISYS	Research Assistant	35 minutes
8 months corrected age	Mail	Overview of NIOS/ Protocol, Completion of Ages and Stages Questionnaire	Research Assistant	15 minutes
9 months post-discharge	Clinic	Overview of NIOS/ Protocol, Completion of the Unscheduled Use Medical Facilities/ HRQOL/Social Services Survey – Month 9	Research Assistant	20 minutes
12 months post-discharge	Clinic	Overview of NIOS/ Protocol, Completion of Demographics survey/ Housing/ CRISYS/ MHLC/ Social Support Survey/ SF-36, Unscheduled Use Medical Facilities/ HRQOL/ and Social Services Survey – Month 12	Research Assistant	1 hour 15 minutes
12 months corrected age	Mail	Overview of NIOS/ Protocol, Completion of PSI/ Impact on Family/ Ages and Stages Questionnaire	Research Assistant	30 minutes

† If an interview could not be completed in person in the clinic or NICU, the research assistant would attempt to collect the information by telephone or by mail.

APPENDIX C. PRESENTATIONS MADE BY THE PROJECT ACCESS TEAM

Fuller J, Hirschman J, Barnickol L, Srinivasan G, Nimmagadda S, Lee K, and Wall S. "The Impact of Legal Services and Case Management on High Risk Infants and Their Families: A Randomized Controlled Trial of Project Access." Pediatric Academic Society's Annual Meeting. Washington DC, May 14-17, 2005.

Nimmagadda S, Hirschman J, Barnickol L, Srinivasan G, Justicz J, Lee K, and Msall M. "Barriers to Early Intervention Services for Impoverished, Very Low Birth Weight Infants: Results from a Randomized Clinical Trial of Case Management and Legal Advocacy." Pediatric Academic Society's Annual Meeting. Washington DC, May 14-17, 2005.

Srinivasan G, Esparza M, Hirschman J, Barnickol L, Nimmagadda S, and Justicz J. "Improvement of Clinic Attendance - Social Services Model." Pediatric Academic Society's Annual Meeting. Washington DC, May 14-17, 2005.

Hirschman J, and Barnickol L. "Research & Evaluation: Measuring the Impact, Examples from Project Access." Family Advocacy Program's, The Medical-Legal Collaboration: A New Era for Child Health. Boston Medical Center, Boston, MA. November 5, 2004.

Barnickol L, Hirschman J, Fuller J, Esparza M, Mister E, and Justicz J. "Impact of Research Site Differences on Case Management Service Delivery to Mothers of Medically High-Risk Infants." American Public Health Association Annual Meeting. Washington DC. November 6-10, 2004.

Hirschman J, Barnickol L, Esparza M, Mister E, and Justicz J. "Housing Advocacy for Low-income Mothers and their High-Risk Infants: Experiences of Project Access." American Public Health Association Annual Meeting. Washington DC. November 6-10, 2004.

Fuller J, Hirschman J, Barnickol L, Nimmagadda S, Robin B, Singh J, Srinivasan G, and Wall S. "Life Stress and Parenting Stress in Mothers with High-Risk Infants – A Descriptive Study." Pediatric Academic Society's Annual Meeting. San Francisco, May 1-4, 2004.

Barnickol L, Hirschman J, Fuller J, Srinivasan G, Nimmagadda S, and Wall S. "Do Indigent, High-risk Infants Need Legal Advocacy to Receive Health and Welfare Services?" American Public Health Association Annual Meeting. San Francisco, CA. November 15-19, 2003.

Hirschman J, Fuller J, Barnickol L, Srinivasan G, Wall S, and Justicz J. "A Randomized Controlled Trial of a Medical-Legal Collaboration to Improve Maternal and Infant Health: Results from the NICU Infant Outcomes Study (NIOS)." American Public Health Association Annual Meeting. San Francisco, CA. November 15-19, 2003.

Hirschman J, Fuller J, Barnickol L, Srinivasan G, Nimmagadda S, Singh J, and Justicz J. "Starting a Medical-Legal Collaboration: Insights from the Field." Family Advocacy Program's, The Medical-Legal Collaboration: Innovative Strategies for Improving Child Health. Boston Medical Center, Boston, MA. October 17-18, 2003.

Hirschman J, Fuller J, Barnickol L, Srinivasan G, Nimmagadda S, Singh J, and Justicz J. "Does Providing Hospital-Based Legal Aid Improve Access to Critical Medical and Welfare Services for High-risk Infants? Results from the NICU Infant Outcomes Study (NIOS)." International Conference on Urban Health. New York, NY. October 15-18, 2003.

Fuller J, Hirschman J, Barnickol L, Srinivasan G, Nimmagadda S, Lee K, and Wall S. "Do Indigent High-risk Infants Need Legal Advocacy to Receive Health and Welfare Services?" Academy Health Annual Research Meeting. Nashville, TN. June 27-29, 2003.

Justicz J. "Promoting Healthy Communities: Project Access." Comprehensive Quality Care Conference. Chicago, IL. May 20, 2003.

Fuller J, Hirschman J, Barnickol L, Srinivasan G, Nimmagadda S, Lee K, and Wall S. "Do Indigent High-risk Infants Need Legal Advocacy to Receive Health and Welfare Services?" Pediatric Academic Societies' Annual Meeting. Seattle, WA. May 3-6, 2003.

Hirschman J, Justicz J, Wall S, and Barnickol L. "Research and Evaluation for the Medical-Legal Collaboration." Family Advocacy Program's, Fostering Medical & Legal Collaborations: How to Bring Legal Advocacy to the Clinical Setting. Boston Medical Center, Boston, MA. October 26, 2002.

Justicz J. "Collaborating to Coordinate Services for Children with Disabilities." National Academy of Social Insurance's National Dialogue on SSI Childhood Disability. Washington, D.C. March 12, 2002.

Wall S, Justicz J. "Partners in Access/Partners in Care: Building Medical-Legal Collaborations to Improve Child Health." National Legal Aid and Defender Association and American Bar Association Equal Justice Conference. Cleveland, OH. April 19, 2002.

Wall S, Justicz J. "Partners in Access/Partners in Care: Building Medical-Legal Collaborations to Improve Child Health." NLADA Program Directors Conference. Milwaukee, WI. November 16, 2001.



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