



Unmet Needs Project: A Research, Coalition Building, and Policy Initiative on the Unmet Needs of Infants, Toddlers, and Families

Final Report

A joint project of the

**University of Illinois at Chicago
Department of Disability and Human Development**

**Erikson Institute
Irving B. Harris Infant Studies Program**

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The success of the Unmet Needs Project was based on the many contributions of families, providers and administrators across the state of Illinois, as well as the expert guidance provided by the project's Steering Committee and Coalition.

We would, first and foremost, like to thank the many families who shared their concerns, needs, and experiences with us. We deeply appreciate the fact that these families took the time to answer our many questions. The experiences that these families shared and their many suggestions served as a rich baseline for the recommendations of this project.

We would also like to thank the many service providers and administrators in this state for their contributions to the Unmet Needs Project. Hundreds of providers from agencies in Illinois took the time to complete our surveys, providing us with solid data on which to build recommendations to enhance services for the children and families that they serve.

From the beginning the project was conceived of as a joint effort, first between the two sponsoring agencies, Erikson Institute and the University of Illinois-Chicago and then in collaboration with our Partner Agencies: Family T.I.E.S. Network, Ounce of Prevention Fund, and Voices for Illinois Children. The Steering Committee of partner agencies played a central role in advising the project, linking its efforts with other policy initiatives, and disseminating the findings to key policy-makers. We are grateful to Voices for Illinois Children for convening the Unmet Needs Project Coalition and thank each member of the Steering Committee for their unique and seminal contributions to the project: Kim Fitzgerald, Gaylord Gieseke, and Jerry Stermer, Voices for Illinois Children; Paula Casas, Karen Freel and Nancy Shier, Ounce of Prevention Fund; and Bill Kienzle, formerly of Family T.I.E.S. Network. We also thank Vince Alloco, El Valor and Wynetta Frazier, Child and Family Development Center, University of Illinois-Chicago for their work on the Steering Committee.

We owe much to the nearly 100 members of the Unmet Needs Project Coalition—parents, service providers, program directors, local and state agency administrators, and advocates. We had hoped that the Coalition would assist in establishing priorities for this project, reviewing research results, and developing recommendations for action. The members of the Coalition more than met these goals and were particularly helpful in establishing social/emotional issues as a key area of unmet needs.

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The Illinois Council on Developmental Disabilities created this initiative on the unmet needs of infants, toddlers, and families. We were privileged to contribute to their vision for young children and families. We thank the current and recent staff members of the Illinois Council on Developmental Disabilities for their ongoing support, guidance and patience.

The Unmet Needs Project was truly a joint effort. Because of the help of many, much was accomplished.

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Part I: Historical Context and Overview

The contents of this report were developed under a grant from the Illinois Council on Developmental Disabilities. However, these contents do not necessarily represent the policy of that agency.

Historical Context and Overview

In the provision of early intervention services for young infants and toddlers, public policy and government funding and support have lagged behind scientific and research findings that confirm the importance and positive long term impact of promoting children's development in the first few years of life¹⁻⁶. The Unmet Needs Project was initiated in order to examine the extent to which current public policies regarding developmental issues are meeting the needs of infants, toddlers and their families in Illinois.

At the time the Illinois Council on Developmental Disabilities released the Request for Proposal (RFP) for the Unmet Needs Project, the eligibility for Part C Early Intervention (EI) services had been restricted to children with medical diagnoses or with a developmental delay of 40% or more in one area.⁷ This change eliminated services for children entering the system with less than severe development delays and for children at-risk. The Council was concerned about how communities could meet the needs of the children who are at-risk or with mild and moderate delays and who were no longer eligible for early intervention.

Further, there was concern about how children were identified for early intervention. The state of Illinois has multiple agencies that conduct Child Find, a public outreach and developmental screening effort, in order to identify children with developmental delays. However, historically there has been a lack of coordination among agencies in collecting, organizing, and analyzing the child findings. The U.S. Department of Education, Office of Special Education (OSEP) had cited Child Find as an area of particular concern in their federal review of Illinois' early intervention system.⁷ Because a coordinated system of child-find activities is needed as the foundation of service planning for children at risk for, or with developmental delays or disabilities, it was important to examine how children are identified as needing early intervention.

Finally, there was concern about the quality of life for children and families in early intervention. What access do families have to services beyond those required by early intervention? These services include but are not limited to child care, medical care, respite services, recreation programs, transportation and mental health services.

To address these concerns, the Erikson Institute and the University of Illinois-Chicago responded to the Illinois Council on Developmental Disabilities RFP and were funded for three years (1999-2002) to implement the Unmet Needs Project. The project's mission was three-fold:

- 1) to conduct research on the unmet needs of infants, toddlers, and families
- 2) to build a broad-based coalition of parents, providers, advocates, and agency representative to consider research findings and to develop policy recommendations
- 3) to make relevant information and policy recommendations available to state-level decision makers on a timely basis to impact policy decisions and programs for infants and toddlers at risk for, or with developmental delays or disabilities, and their families.

To expand the impact of the Unmet Needs Project, the collaborating institutions—the Erikson Institute and the University of Illinois-Chicago—formed a partnership with three key statewide advocacy organizations: Family T.I.E.S, Ounce of Prevention Fund, and Voices for Illinois Children. These organizations served on the Project’s Steering Committee and played a key role in advising the project, linking its efforts with other early childhood policy initiatives, and disseminating the findings to key policy-makers.

The following report presents the goals, major activities and outcomes of the project related to its three-fold mission: coalition-building, research, and policy recommendations.

Goal I: Establish and Support an Effective Coalition

The report summarizes the development of the Unmet Needs Project Coalition, its role and accomplishments and the role and functioning of the Steering Committee.

Goal II: Conduct a Research Program to Support Policy Development

The report describes the research studies conducted in the three target areas, presents a summary of the findings, and the policy outcomes related to each area of study. The full findings for each study area are presented in the Appendices. The three target areas are:

Study One: Unmet needs of children with mild delays not eligible for early intervention and their families

Study Two: Unmet needs of children and families in early intervention for non-required services beyond Part C early intervention

Study Three: Unmet needs of children at risk, particularly the availability of developmental screening and infant mental health services.

Goal III: Develop and Build Support for Strategic Planning and Policy Development

The report describes the state planning and policy development efforts that will continue to build on the recommendations and outcomes of the Unmet Needs Project to impact services for infants, toddlers, and the families in Illinois.

Part II: Project Goals, Activities and Outcomes

Project Goals, Activities and Outcomes

GOAL I: Establish and Support an Effective Coalition

A. Project Activities

1. Steering Committee

a. Committee Members A Steering Committee of the Project Partners guided the development of the Coalition and served as an executive committee for the project. Over the course of the project, Steering Committee members included:

Vince Alloco, Executive Director
El Valor

Gaylord Gieseke, Vice President
Voices for Illinois Children

Paula Casas
Ounce of Prevention Fund

Bill Kienzle
Family T.I.E.S. Network

Kim Fitzgerald
Voices for Illinois Children

Nancy Shier, Director
Kids Pepp, Ounce of Prevention Fund

Wynetta Frazier
Child and Family Developmental Center
University of Illinois at Chicago

Jerry Stermer, President
Voices for Illinois Children

Karen Freel, Vice-President
Ounce of Prevention Fund

b. Committee Activities. The Steering Committee met regularly throughout the project to plan and evaluate Coalition activities and to advise on project activities. During the first two years, weekly communication was maintained via Friday e-mail updates regarding the progress of the project and relevant state news. The Steering Committee served as a liaison to other key policy initiatives including the Birth to Three Project¹.

* The Birth to Three Project is a partnership between the Ounce of Prevention Fund and state government agencies that began in the fall of 1998. Funded by the Robert Wood Johnson Foundation, the Project is a statewide, multi-year, multidisciplinary effort to develop a comprehensive, coordinated, high-quality system of birth to three services throughout Illinois. The Project is led by a State Work Group and five working committees that address key areas relevant to children under three: Social and emotional health, best program practices and outcomes, systems coordination, training and workforce development, and linkages to health care. As part of the Project, the Illinois Department of Human Services has provided funding to pilot All Our Kids: Birth to Three Networks in ten Illinois communities to build a system of prevention services at the local level that maximizes the use of existing resources.

In turn, participation in the project provided Steering Committee members with an ongoing forum for discussion of a range of issues, particularly early intervention concerns and contributed to their advocacy efforts for infants and families. The work of the Steering Committee culminated in a project retreat during Year III to review the project's work and to consolidate and prioritize recommendations for action in preparation for the final Coalition Meeting.

2. Unmet Needs Project Coalition

a. Coalition Members. The first goal of the project was to establish an effective coalition of parents, providers, state agency representatives and advocates to advise the project and to assist in formulating and advocating for systems improvement and change. Initiated in April, 1999, with over 90 members including parents, service providers, advocates, and local and state agency representatives, the Coalition represents geographically diverse regions of the state with approximately one-third of the membership from central and southern Illinois. Convened by project partner, Voices for Illinois Children, the coalition met 7 times over the course of the project.

b. Coalition Activities. As a group, the Coalition was actively involved in identifying the unmet needs of infants, toddlers, and families in Illinois, setting priorities for the project, providing feedback on the research plan and survey and interview tools, interpreting study findings, and developing recommendations for action. Further, individual coalition members generously contributed their expertise and resources to the project. For example, Claudia Fabian, Illinois Migrant Head Start, translated the Child Care Family Survey and accompanying parent letter into Spanish. Anne Shannon, Executive Director of Aspire and Chair, of Illinois Interagency Council for Early Intervention, arranged for a company to donate its services to laminate 900 posters about the Child and Family Connection that were sent to physicians as apart of the Primary Care Survey. Faye Eldar, parent advocate, advised in the development of the parent survey.

c. Catalyst for Action. The Unmet Needs Project Coalition provided the stimulus for the development of two key statewide forums for advocacy and systems development: Ad Hoc Advocacy Group for Early Intervention and the Statewide Social and Emotional Committee.

Ad Hoc Advocacy Group for Early Intervention: In October, 2000, the Illinois Department of Human Services informed the Early Intervention community that it was anticipating a \$63 million budget shortfall in the Early Intervention System. Their main proposed solution was to change eligibility for Early Intervention to a 50% or greater delay and then – if there were funds left over -- serve the other children in a new program called Early Start. It was evident this proposal would leave out significant numbers of children with 30-49% delays and all children at risk of a delay – the very group of children that often make significant gains with services and supports. Voices for Illinois Children and the Ounce of Prevention Fund, members of the Unmet Needs Steering Committee, brought together a number of coalition members and other interested parties in Illinois and formed the Ad Hoc Advocacy Group for Early Intervention.

This group met on a monthly basis and organized a number of strategies to ensure that all infants and toddlers with a 30% or greater delay would receive services in the Early Intervention system

and therefore be guaranteed services under the federal and state law. Members of the group were active in educating legislators about the importance of early intervention, helping to research other funding mechanisms (such as billing Medicaid and using private insurance) and informing the media about the impact these changes would have on children and families. Many of the Ad Hoc Group's ideas and strategies came together in a piece of legislation, Senate Bill 461, which was passed by the General Assembly and signed into law in 2001. Many positive changes to the Early Intervention system were made possible because of the Ad Hoc Advocacy Group, which benefited from the quick response of many of the Unmet Needs Coalition members. The Ad Hoc Advocacy Group remains connected through a monthly e-mail update and meetings when needed.

Statewide Social and Emotional Committee: The establishment of the statewide Social and Emotional Committee is a major outcome of the Unmet Needs Project. This committee was established in the summer of 1999 as a result of issues identified at the second Coalition meeting and of parallel findings regarding the lack of mental health services for very young children and families by the Ounce of Prevention in planning for the Birth to Three Project. The Committee is a partnership of the Unmet Needs Project, the Ounce of Prevention Fund's Birth to Three Project, Voices for Illinois Children, and the Illinois Association for Infant Mental Health. Dr. Cutler served as a co-chair representing the Unmet Needs Project. The Committee will continue to function as part of the Birth to Three Project and is staffed by the Birth to Three Project. At this time, the Committee includes over 50 members. The priorities for committee actions are: 1) Screening, Assessment and Referrals across early childhood programs, 2) Consultation and training to early childhood programs and providers regarding the promotion of social and emotional development and intervention strategies when needed, and 3) Availability of early childhood mental health diagnostic and treatment services across the state. The Committee has helped to establish the Children's Mental Health Task Force, through the Illinois Violence Prevention Authority, which has as its goal to develop a statewide plan to address the mental health needs of children birth to age eighteen by January 1, 2003.

B. Coalition Outcomes

- Unmet Needs Project Coalition representing parents, providers, state agency representatives and advocates was established and functioned successfully throughout the project.
- Steering Committee of Partner agencies played a central role in advising the project, linking its efforts with other policy initiatives, and disseminating the findings to key policy-makers.
- Coalition served as a catalyst for two state forums for systems change: Ad Hoc Advocacy Group for Early Intervention and statewide Social and Emotional Committee.
- As a result of the efforts of the project, its Coalition and Steering Committee, a comprehensive set of recommendations based on project findings was developed and used to impact planning and policy developments for infants, toddlers, and their families.

GOAL II: Conduct a Research Program to Support Policy Development

The research program was designed to examine the needs of three groups of children:

- Study One: Unmet needs of children with mild delays not eligible for early intervention and their families
- Study Two: Unmet needs of children and families in early intervention for non-required services beyond Part C early intervention
- Study Three: Unmet needs of children at risk, particularly the availability of developmental screening and infant mental health services

STUDY ONE: UNMET NEEDS OF INFANTS AND TODDLERS WITH MILD DEVELOPMENTAL DELAYS NOT ELIGIBLE FOR EARLY INTERVENTION AND THEIR FAMILIES

A. Project Activities

Study One was designed to assess the needs of children with developmental delays who were not eligible for Part C Early Intervention Services. At the time the grant was written, the eligibility criteria for developmental delay had been raised from 20% delay to 40% delay. The study was to examine the impact of this change on families and community services. Key questions were: how many children are effected by the eligibility change, what services are available for these children and how easy/hard is it for families to access services, and how satisfied are families and communities with services available. The study plan included phone interviews with parents, a CFC¹ (Child and Family Connections) Coordinator Survey of community resources, and retrospective chart reviews. Parent interviews were developed and piloted; 4 CFCs were identified by the Bureau of Early Intervention; a CFC orientation meeting was held; and the study was launched with collaborating CFC's: Chicago North, Freeport, Macomb, and Belleville.

However, by the time the study was launched, ongoing changes in Early Intervention policy placed new time demands on the CFCs related to added responsibilities for service coordination, and eligibility criteria had decreased to 30% delays. Thus, the study could not be completed as planned. An alternative strategy was designed to gather relevant data. Information on the service needs of children with milder delays was obtained by adding questions to prevention, child care, and early intervention providers on the Developmental Screening Surveys. The results revealed that:

¹ Child and Family Connections are the entry points to the Part C Early Intervention Services in Illinois.

- 66% of communities do not have adequate services to meet the needs of children with mild developmental delays.
- 76% of prevention programs and 37% of child care programs are serving children with mild developmental delays and that they offer these children their typical program services.
- Prevention and child care programs do not have access to developmental specialists, occupational therapists, and other specialists to assist them in planning for or serving these children.

These data were presented to state agency and community leaders at two forums: Unmet Needs Project Coalition and Birth to Three Project State Work Group. Further, the Illinois Department of Human Services requested a copy of the findings in Fall, 2000, when the Department was considering a new round of eligibility changes, including raising the level of developmental delay to 50% because of a projected budget shortfall.

Clearly, the findings showed that communities did not have adequate services outside of the early intervention system to absorb these children. The findings were presented by the project at an Illinois Department of Human Services Public Hearing held in Fall, 2000 in regard to proposed changes to advocate for the maintenance of children with mild delays within the early intervention system. Further, the findings stimulated discussion in the Coalition and the development of an Unmet Needs Project Recommendations for Action regarding the need for specialized developmental consultation to prevention and child care programs regarding the needs of children with mild developmental delays.

B. Developmental Delay Outcomes

- Data were obtained on the inadequacy of community services for children with mild developmental delay.
- The findings were presented to key decision-makers in a timely manner and were used to advocate for policies that would enable children with mild developmental delays to continue to receive early intervention services.
- Unmet Needs Project developed Project Recommendations for Action regarding the need for specialized developmental consultation for prevention and child care programs and began the discussion in policy forums toward this long-term goal.

STUDY TWO: UNMET NEEDS OF CHILDREN AND FAMILIES IN EARLY INTERVENTION FOR NON-REQUIRED SERVICES BEYOND PART C EARLY INTERVENTION

A. Project Activities

The purpose of this study was to assess the needs of families with infants and toddlers with developmental delays or disabilities who were receiving early intervention but who had needs for services not mandated by Part C of the Illinois Department of Human Services (IDHS). Three studies were conducted:

Early Intervention Child Care Family Survey

This study was designed to survey parents of children enrolled in early intervention about their child care needs. This survey was initiated in partnership with and co-funded by the Illinois Map to Inclusive Child Care Project (IMAP), chaired by the late Bob Brocken, of the DHS Bureau of Child Care and a member of the Unmet Needs Coalition. The survey included questions about current child care use, child care needs, qualities and services valued in a child care program, and special services their child may be receiving in a child care setting. The surveys were distributed to families by Early Intervention Programs. The complete findings are presented in Appendix A and summarized below:

- 42% of the parents of children receiving early intervention services reported using child care and 65% of these parents had their children in child care at least 30 hours per week.
- 27% of parents using child care reported having had child care denied and at least half of these denials were related to their child's special needs. Another 10% of denials occurred because of behavioral issues.
- Most of the parents who reported not using child care had chosen to be at home or were not working. However, 25% of these parents reported an inability to access child care because:
 - it was not affordable
 - lack of quality
 - the inability of programs to meet their child's special needs.
- 65% of parents reported work, school or job training difficulties because of problems in finding or keeping child care. 4% reported losing their job because of lack of child care.

Early Intervention Parent Survey

This study was designed to survey parents of children currently receiving early intervention about needs of their child and family for services not covered by Part C of IDEA. The survey was developed in collaboration with the Family Committee of the Illinois Interagency Council on Early Intervention* and other family advocates including the Unmet Needs Project Steering Committee members. The survey included questions about the need for and access to childcare, respite care, medical treatment, transportation, and infant mental health services. 101 families responded to the survey, which was distributed to them through their early intervention program. The complete findings are presented in Appendix B and summarized below:

- The majority of parents surveyed reported not having been informed of respite services or recreational programs for their children with special needs.
- Although 97% of these families had insurance coverage for their children, families have had to withhold or delay medical care because of lack of insurance reimbursement for needed services. A significant number of the challenges that parents listed related to medical issues involved the logistics of getting their children to medical appointments (obtaining time off work, finding child care for their other children, the travel involved) rather than the quality of the medical care itself.
- Almost 50% of these parents stated that their child had behavior problems for which they needed help in managing. Difficulties with sleep or feeding were the most frequently cited issues, but a wide range of behavioral issues were mentioned.
- Early intervention providers were cited as the chief source of help for parents regarding behavioral issues, followed by physicians, family members and friends. Half of the families voiced a need for counseling services to help their family handle their child's behavior problems.
- When asked what would improve the quality of life for their children, families mentioned the need for improved qualifications of the therapists working with their children and the need for support groups for families.

* The Illinois Interagency Council on Early Intervention (ICEI) is an advisory body to the governor consisting of parents of children in early intervention, early intervention providers, and representatives from state agencies.

Early Intervention Parent Focus Groups

This study was designed to involve parents of infants and toddlers enrolled in early intervention programs at local community sites in geographically diverse locations across the state in focused group discussions of their need for non-required Part C services. Questions were prepared to probe the need for and ease of access to child care, respite care, medical treatment, transportation, recreation services, non-traditional treatments, family counseling and infant mental health services.

Four focus groups were held across the state. Two groups were held in the Chicago area: one with low-income African-American parents and one conducted in Spanish with Latino parents. Two additional groups with predominantly Caucasian parents were held in Springfield and in Decatur. Two additional parents from Shelbyville participated in individual interviews. The complete findings are presented in Appendices A and B and highlights from the focus groups are presented below:

- The parents of the focus groups confirmed the findings from the parent surveys (as discussed above) regarding:
 - Their lack of information about respite services and recreational programs in their communities
 - The difficulty of finding quality, inclusive child care
 - The need for family counseling and assistance with child behavior concerns
- Although the majority of parents surveyed (see above study) reported satisfaction with their child's current health care provider, many parents in the focus groups reported difficulty finding a physician who understood developmental and/or behavioral issues. Multiple examples were given of physicians who failed to respond to parental concerns. Parents reported difficulty in finding physicians who understood their concerns and described this as a significant source of stress and as delaying needed treatment for their child.
- Families in early intervention are under a great deal of stress and feel overwhelmed at times from managing their child's therapies, coping with the challenges of children's behavior problems, trying to balance work with family demands and deal with tensions with the marriage and family.
- Families want and need more emotional support than they are currently receiving from early intervention. "No one asks how are you?" Parents want to talk with someone trained to go beyond the initial "I'm fine." Families are not routinely offered social work or psychological support as part of the IFSP (Individual Family Service Plan) process and they feel families should have the opportunity to receive these services.
- Child behavior problems are a major area of concern for families. The help they currently receive is not adequate. They seek support from persons who know about developmental disabilities and behavior problems.

- Parents are not receiving parent-to-parent support. They would like to see more opportunities for parent-to-parent contact as a part of early intervention services.

B. Non-Required Services Outcomes

- The survey results and focus group findings were presented to the Special Advisory Panel on Early Childhood Development Sub-Committee on Social/Emotional Development, a committee formed by the Department of Human Services to advise the lead agency for Part C on the social/emotional needs of infants, toddlers, and families. The committee is chaired by Dr. Gilkerson, Project Co-Director. The Unmet Needs Project findings and recommendations provided a foundation for the sub-committee's recommendations to the lead agency on parent-to-parent support, recreation and respite services, and parent counseling. These recommendations were presented to the Panel in January, 2002.
- In February, 2002, Carolyn Cochran Kopel, DHS Associate Secretary responsible for the Early Intervention program, initiated a pilot in 3 CFC areas to implement the Part C Social/Emotional Sub-Committee's recommendations. The CFC areas are: Southwest Chicago, Joliet, and Bloomington. This pilot project represents a promising effort to move from recommendations to action regarding much needed additional family support in early intervention and assistance with child behavioral concerns. The Unmet Needs Project surveys and focus group data and the leadership provided by the Unmet Needs Project made a significant contribution to this effort.

STUDY THREE: UNMET NEEDS OF CHILDREN AT RISK, PARTICULARLY THE AVAILABILITY OF DEVELOPMENTAL SCREENING AND INFANT MENTAL HEALTH SERVICES

Study Three focused on two primary areas of unmet needs for at risk infants and toddlers: (a) access to quality developmental screening and (b) need for infant mental health services for infants, toddlers, and their families. These survey areas are described below.

Developmental Screening Surveys

A. Project Activities

A comprehensive developmental screening survey was developed and mailed statewide to over 2,400 providers to assess the screening capability of the primary settings where developmental screening for infants and toddlers occurs. These settings included prevention programs, early intervention programs/CFCs, child care centers, public health clinics, and pediatrician/family physicians offices. The survey included questions about developmental screening outcomes, procedures, referral protocols, and available services for children ineligible for early intervention. Five versions of the survey were prepared in order to tailor to the needs of each of the settings listed above. The complete findings are included in Appendix C; a summary of the highlights is presented below.

- A high percentage of public health, prevention, early intervention and primary health care providers provide or arrange for developmental screenings. Child care programs are less likely to provide or arrange for screenings.
- 10-13% of children do not pass the screenings in prevention, child care programs, and pediatric settings. Family physicians reported the lowest percentage (3%) of children who fail screenings and had less knowledge of the CFCs, the entry point for early intervention services.
- While best practice standards recommend the use of a standardized tool for screening, child care programs and physicians are least likely to use a formal instrument, preferring agency developed checklists or clinical judgment. For programs that use tools, the Denver is the most frequently utilized tool. There is a need for training in developmental screening procedures and in newer, alternative tools.
- Programs differ in their referral sources. Prevention and public health programs refer first to CFCs. Physicians are most likely to refer to private providers/agencies; child care program staff are most likely to refer to the public schools.
- One of the most striking findings was that 55% of infant/toddler child care programs have no knowledge of the Child and Family Connections, the entry point into the early intervention system.

B. Developmental Screening Outcomes

- The first statewide survey of developmental screening procedures for infants and toddlers in Illinois was conducted.
- The project disseminated the developmental screening findings to state-level policy makers at 4 forums: Unmet Needs Project Coalition, Birth to Three Project, IMAP Project, and Illinois Chapter of the Academy of Pediatrics.
- Dissemination of findings to the IMAP project served as a catalyst for the development of a statewide plan to train infant/toddler child care providers to conduct developmental screenings; the proposal was developed by the IMAP project at the request of the Child Care Bureau. The developmental screening training has been approved for funding to begin in July, 2002.
- The dissemination of findings to the Illinois Chapter of the Academy of Pediatrics led to the formation of a Developmental Screening Subcommittee at the Academy, which Dr. Cutler has been asked to chair. The initiation of this Subcommittee implements the Unmet Needs Projects recommendations for training of pediatricians in developmental screening and for targeting family physicians for training—the group that sees the largest number of children and has the least knowledge of developmental screening practices and early intervention services.
- The dissemination of findings to the Birth to Three Project lead to consideration of the Unmet Needs Project recommendations by the Birth to Three Project agenda. The Co-Directors of this study served on the Birth to Three Project's Ad Hoc Developmental Screening Subcommittee and worked collaboratively to advocate for policies requiring that infant/toddler programs that receive state funding be required to provide children with developmental screening.
- The information has been shared more broadly in Illinois through publication in a Birth to Three Project newsletter⁸. Further, the developmental screening findings were recently published in the Illinois Pediatrician (Fall, 2001), the newsletter of the Illinois Chapter of the American Academy of Pediatrics.⁹ These findings will also be submitted to a family physician journal or newsletter. The findings are particularly timely for a pediatric audience, as the American Academy of Pediatrics has just published their recommendations for developmental surveillance and screening.¹⁰ The findings will also be submitted to *Infants and Young Children*, one of the major journals for birth to three professionals and in the Child Care Information and Exchange (CCIE), a publication that reaches child care directors nationwide.

Illinois Infant Mental Health Survey

A. Project Activities

The Unmet Needs Project conducted the first statewide infant mental health survey to assess the incidence of social/emotional/and behavior concerns in infants, toddlers and families, as well as services provided in their communities, and services that are needed. The survey was conducted as part of the Unmet Needs Project's leadership role in the statewide Social and Emotional Committee (see discussion page 12). Over 600 programs providing prevention, early intervention, public health and child care services were surveyed. The complete findings are included in Appendix D; highlights are presented below.

- 16% of infants and toddlers in programs surveyed have social/emotional/behavioral concerns. While most of these were concerns that respond to regular program services, 7% were severe, requiring additional intervention and/or urgent care.
- Over 40% of child care programs have had to ask a child to leave the program because of social/emotional/behavioral problems. In group care, the most challenging behaviors are biting, hitting, and aggressive behavior.
- Programs serve families with mental and behavioral health problems. The greatest challenge for staff is working with families where there is mental illness, child abuse or neglect, or domestic violence. Program staff most want specially trained staff or consultants to work with them on an ongoing basis around these difficult challenges.
- Only 30% of programs reported they were adequately prepared to meet the social/emotional mental health needs of children and families they serve. 80% of programs identified training in infant mental health as a priority for staff development.
- 62% of the communities do not have adequate services to meet the mental health needs of infants, toddlers and families.

B. Infant Mental Health Outcomes:

- The project conducted the first statewide survey of infant mental health in Illinois.
- The findings were disseminated to state policy-makers through the Unmet Needs Coalition, Illinois Association for Infant Mental Health, Birth to Three Project State Work Group, the statewide Social and Emotional Committee, and the Special Advisory Panel on Early Childhood Development.
- At the request of Secretary Baker, the Co-Directors developed an Executive Summary of the Survey for the Department of Human Services (See Appendix E). The survey findings provide state administrators with the first estimates of the prevalence of

social/emotional concerns in infants/toddlers, perceptions of providers regarding the availability of program and community resources to meet these needs, and the unmet needs in Illinois regarding infant/family mental health.

- Findings from the survey, in concert with the focus groups findings, were used by the Special Advisory Panel on Early Childhood Development Sub-Committee on Social/Emotional Development to develop recommendations for mental health services and family support in the early intervention system. The exciting breakthrough, as noted above, is that these recommendations are providing the basis for a pilot project in 3 CFC areas: Southwest Chicago, Joliet, and Bloomington. As a result, these areas will pilot:
 - A relationship-based approach to early intervention for all families, emphasizing emotional support, parent/child relationships, and parent-to-parent support
 - Reflective supervision for service coordinators and providers
 - Social/emotional screenings for all children evaluated for early intervention
 - Specialized follow-up assessment as needed
 - Intervention services for social/emotional and behavioral concerns, including the possibility of mental health consultation
- As a result of the multiple efforts in Illinois related to infant mental health, in April 2002 an intra-divisional team of the Illinois Department of Human Services held a focus group to discuss the mental health needs of infants and toddlers served through their various programs. The Unmet Needs Project Infant Mental Health Survey Child Care was presented at the focus group to highlight the level of concern about social/emotional problems in child care and the needs of child care providers for training and consultation.
- The findings were also presented to the Zero to Three: National Center for Infants, Toddlers, and Families Infant Mental Health Task Force, co-chaired by Dr. Gilkerson. This group seeks to affect training, systems development, recommended practices, and public awareness of infant mental health throughout the 50 states.
- As noted under Coalition Outcomes, the Unmet Needs Project co-founded the first Statewide Social and Emotional Committee. This committee helped to establish the Children's Mental Health Task Force, charged with developing a state plan for children's mental health services by January, 2003. The Illinois Mental Health Survey findings provided key baseline data for committee action priorities.

GOAL III: Develop and Build Support for Strategic Planning and Policy Development

Although the activities associated with Goal 3 were primarily designated for the third year, the Unmet Needs Project contributed to planning and policy development throughout its funding cycle. The accomplishments in planning and policy development detailed in the outcomes above attest to the success of the project in its mission to use research in the service of systems change. These accomplishments were shared successes with the Coalition and the project partners, most notably Ounce of Prevention Fund and Voices for Illinois Children. In many ways, the effectiveness of the Unmet Needs Project was due to its seamless interface with other major initiatives. Rather than duplicating, we magnified each other's efforts, and worked hard together to produce results far exceeding our expectations. Among these were:

- Advocated successfully to maintain children with mild delays within the EI system
- Provided research and leadership to support the initiation and implementation of the Early Intervention Social/Emotional Pilot Project by the Illinois Department of Human Services
- Served as a catalyst for the initiation of two statewide screening initiatives: Developmental Screening Committee of the Illinois Academy of Pediatrics and Child Care Bureau Developmental Screening Initiative in Infant/Toddler Child Care
- Co-founded the Statewide Social and Emotional Committee leading to the formation of the Children's Mental Health Task Force which is charged with the development of a statewide plan for children's mental health services.

The work of the Unmet Needs Project in state planning and policy development will continue after the project through participation in the following forums, each of which has benefited from the research and recommendations of the Unmet Needs Project:

Infant Mental Health

- Birth to Three Project Statewide Social and Emotional Committee
- Children's Mental Health Task Force
- Early Intervention Pilot Project on Social/Emotional Development
- Intra-departmental team of the Illinois Department of Human Services on early childhood mental health
- Zero to Three: National Center for Infants and Toddlers Infant Mental Health Task Force

Developmental Screening

- Birth to Three Project Systems and Best Program Practices and Outcomes and the State/Federal Interagency Team Committees
- Illinois Chapter of the American Academy of Pediatrics Subcommittee on Developmental Screening.
- IMAP Project
- Child Care Bureau Training Initiative on Developmental Screening in Child Care

Needs of Families in Early Intervention for Non-Required Services

- Early Intervention Pilot Project on Social/Emotional Development
- IMAP Project

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About the Institute on Disability and Human Development

The Institute on Disability and Human Development (IDHD) is the federally designated University Center for Excellence in Developmental Disabilities for the State of Illinois, one of 66 similar programs in major universities across the United States. The IDHD is a component of the Department of Disability and Human Development (DHD), and is authorized under the Developmental Disabilities Assistance and Bill of Rights Act to provide interdisciplinary training, technical assistance, program demonstrations and evaluations, and conduct research and policy analysis. Core funding is received from the Administration on Developmental Disabilities in the U.S. Department of Health and Human Services. In addition, IDHD receives funding from a variety of other federal, state, local, and foundation sources. Major externally funded centers within the IDHD include the Center on Emergent Disability, Great Lakes Disability and Business Technical Assistance Center, Assistive Technology Unit, and Diagnostic Clinic. Together, the DHD and IDHD represent one of the nation's largest non-hospital based disability research centers with over 200 faculty and staff committed to 40 disability and rehabilitation-related studies and projects. Activities address a broad range of issues related to disability and human development. As a result, the faculty and staff involved in the projects of the Institute represent many different disciplines and fields of scholarship, including anthropology, kinesiology, law, occupational therapy, pediatrics, physical medicine, physical therapy, psychiatry, psychology, public health rehabilitation engineering, social work, sociology, special education, and speech and hearing sciences.

The programs and services of IDHD are organized around three central themes: Research and Graduate Education, Clinical and Family Support Services, and Technical Assistance and Community Education. While individual programs may predominantly address one of these themes, elements of all three themes can be found within all activities of the Institute. Research programs stress systems-level impacts, the development of new knowledge, and making such knowledge available to practitioners. Clinical programs include the 0-3 Diagnostic Program, an interdisciplinary program that provides diagnostic and family support services for infants and toddlers with developmental and behavioral concerns. Technical assistance and outreach training activities resonate with the research and clinical activities, bridging the Institute to the community and helping to focus Institute activities on relevant issues and concerns in the field.

About the Erikson Institute

Erikson Institute is an independent institution of higher education that prepares child development professionals for leadership. Through its academic programs, applied research, and community advocacy, Erikson advanced the ability of practitioners and researchers to improve life for children and their families. The Institute is a catalyst for discovery and change, continually bringing the newest scientific knowledge and theories of children's development and learning into its classrooms and out to the community so that professionals serving the family are informed, inspired, and responsive.

Established in 1985, the Irving B. Harris Infant Studies Program is an 18-credit, post-baccalaureate specialist training program for professionals from a range of disciplines. Through summer coursework, internship, and reflective supervision, students are prepared to work with infants and toddlers and their families in hospital settings, prevention and early intervention programs, child care and family support programs. Participants can specialize in the areas of prevention/early intervention, child care, or infant mental health. The infancy specialization is also available through the master's program.

Appendix A

Unmet Needs Project

Findings at a glance: Child Care for Infants and Toddlers in Illinois

Multiple Perspectives on Child Care for Infants and Toddlers

The Unmet Needs Project assessed a variety of issues related to child care in Illinois from the perspective of parents and child-care providers. Specifically, the following studies were conducted:

Assessing the Perspectives of Parents

- **Early Intervention Child Care Family Study**

This study assessed the perspectives of parents of children who were receiving early intervention services regarding their child care needs and experiences. Data was collected from January-December, 1999.

642 surveys were mailed to families identified through early intervention programs.
126 surveys were returned completed (20% response rate).

- **Early Intervention Parent Focus Groups**

Parents of children receiving early intervention services participated in focus group discussions regarding their child care needs.

4 focus groups were conducted: two in Chicago, one in Decatur, and one in Springfield.
32 parents participated.

Assessing the Perspectives of Child Care Providers

- **Child Care Program Inclusion Survey**

This survey gathered information regarding the inclusion practices of center-based infant-toddler child care programs.

200 surveys were mailed to center-based child care program directors.
89 surveys were returned completed (44% response rate).

- **Child Care Infant Mental Health Survey**

This survey was part of a larger study that obtained information on the social/emotional concerns that providers (child care, early intervention, prevention and public health) are seeing among the children and families they serve.

195 surveys were mailed to center-based child care programs.
75 surveys were returned completed (38% response rate).

- **Child Care Developmental Screening Survey**

This survey was also part of a larger study that assessed the developmental screening practices of center-based child-care programs, early intervention, prevention and public health providers and primary care physicians across the state of Illinois.

200 surveys were mailed to center-based child care program directors.
89 surveys were returned completed (44% response rate).

Parents' Perspectives: Early Intervention Child Care Family Survey

- Survey response rate (number of surveys mailed/returned)
20% (126/642)
- 42% of parents reported using child care for their children receiving early intervention (EI) services.
- Parents reported the following reasons for using child care:
 - 51% Parents are working
 - 17% Parents are in school
 - 15% Help with child's development
 - 10% Individual Family Service Plan* (IFSP) recommendation
- Parents who do not use child care reported:
 - 31% Not working
 - 30% Choose to be home
 - 11% Cannot afford child care**
 - 6% Lack of quality care
 - 5% Programs cannot meet needs of child
 - 3% Program will not accept child
- 23% of parents who were not using child care reported that they would like to do so.
- Child care used included:
 - 29% Family members
 - 26% Day care centers
 - 16% In home care
 - 10% Family day care
 - 3% Early Head Start
 - 3% Center care for children with disabilities
- Parents reported that their children spend many hours in child care.
 - 48% 30-45 hours per week
 - 17% More than 45 hours per week
- 29% of parents reported having had child care denied.

* An IFSP is a document prepared following an evaluation of a child through the state early intervention system.

- Parents reported the following reasons why child care was denied:
 - 26% Inadequate staff training/experience with children with disabilities
 - 17% Child's disability, health care need, or special needs
 - 10% Behavior problems
 - 10% Toilet training issues
 - 8% Not enough staff
 - 6% Extra costs involved with care for their child
 - 5% Lack of health care and medical support
 - 2% Problems with state regulation
 - 2% Poor communication between staff and parents**
 - 2% Lack of special equipment/accessible facilities

- Parents reported that difficulties in finding or keeping child care resulted in:
 - 26% Missed work
 - 14% Inability to work
 - 11% Nothing
 - 7% Unable to attend school/job training
 - 7% Pass up career advancement
 - 5% Delay in going back to work
 - 4% Lost job

- 34% of children receiving child care were receiving special therapies, including:
 - 32% Speech/language therapy
 - 24% Developmental therapy
 - 19% Physical therapy
 - 17% Occupational therapy
 - 2% Behavior therapy

- 95% of these parents reported being satisfied with the child care they were receiving.

- What do parents want most from child care providers?
 - Good communication, especially good listening
 - Adaptive program activities and toys
 - Meet child's nutritional needs
 - Meet child's health needs
 - Guide their child's behavior
 - Be involved in the early intervention process

Parents' Perspectives: Early Intervention Parent Focus Group Child Care Findings

- Parents reported that finding good child care is difficult.
 - Parents voiced concerns regarding the availability of affordable, quality child care.

*We need good quality child care at a reasonable price.**

The help that you find within a family budget is horrible daycare.
 - Parents voiced frustration about not qualifying for child care subsidies. Those who did qualify were grateful.

There is no way I could do without it [state subsidy daycare].

You have to be extremely, extremely poor, destitute to qualify for daycare. It's just not fair.

Parents are separating because they can't be together and make it.
- Using child care for a child with special needs creates additional challenges for parents

Any time you have a child with special needs, they [day care program staff] get automatically disconnected.

They were afraid of him... people would just look at him and they just wouldn't take him.

There was a waiting list [for day care centers that would accept an apnea monitor and a healthy baby with a history of prematurity]
- Programs that accept children with special needs are not always adequately prepared to meet their special needs.

Day care programs are not really prepared to take care of children with special needs. They watch them... but they're not involved with babies with special needs.

They do not have equipment. Everything I had to bring there.

I had to quit my job to take care of him... when I kept him home [from day care] he gained weight (The baby referred to had been failing to gain weight).

* Note: direct quotations from parents are italicized.

- Early Intervention (EI) services are being provided in child care settings, but communication among child care staff, EI providers and parents remains a challenge.

- Child care providers may have difficulty accommodating the schedule of therapists and may not be participating or observing therapies, thereby allowing carry-over of therapeutic techniques (processes) into the day care setting.

They [the child care program staff] wanted only one therapist a week. I was penalized because they only wanted the therapist to come between 9:30 and 10:30.

She [the therapist] takes him out of the room. She doesn't spend a lot of time with the teacher [child care provider].

- Parents may have little or no communication with a therapist providing services in a child care setting.

They provide me with a progress note. Now a PT's [physical therapist's] progress note is like foreign to a lot of people.

The 6 month evaluation is the only time I get to see him [the therapist].

I did my research and I didn't want [my child] to do sign language because it's a unilateral hearing loss... I just happened to stop in [the child care center] and my therapist was teaching my daughter sign language...

- Parents had mixed responses when asked if child care workers should participate in IFSP (Individual Family Service Plan) meetings.

I thought it was a good idea. Because the teachers really weren't sure... why [my daughters] were getting all these services... so it was a teaching process for them to understand...

My provider... there are some things she doesn't need to know about me

When you have an IFSP, you already have so many people in or around, it's no longer just me and my husband's house. It's mine, my husband's, the therapists, the doctors. You just now have too many people in your business.

Child Care Providers' Perspectives: Child Care Program Inclusion Survey

- Survey response rate (number of surveys mailed/returned)
44% (89/200)
- 51% of child care programs surveyed enrolled children with identified delays or disabilities.
- **Child care program directors reported that developmental delays and social/emotional/behavior problems were the most frequent types of delays or disabilities seen in children in childcare.**
 - 95% Developmental Delay
 - 41% Behavior problems/Social/emotional concerns
 - 28% Hearing Impairment
 - 20% Visual Impairment
 - 17% Autism/Pervasive Developmental Disorder
 - 17% Cerebral Palsy
 - 13% Other (including substance exposure, seizures, orthopedic problems)
- Of the programs that had children with developmental delays/disabilities, 81% reported having children who receive early intervention (EI) services.
- Child care program directors reported that child care programs assist in the provision of EI services, primarily through serving as a site for EI services.
 - 80% EI staff provide services on site
 - 24% Program staff carry out interventions in the individual family service plan (IFSP)
 - 20% Program staff have participated in an IFSP meeting
 - 4% EI staff supervise child care staff in providing interventions
- Most child care programs feel at best somewhat prepared to provide child care for infants and toddlers with disabilities.
 - 4% Very prepared
 - 18% Prepared
 - 58% Somewhat prepared
 - 13% Unprepared
 - 7% Very unprepared
- Child care program directors reported that training, technical assistance, materials, and additional staff will help prepare child care providers to service children with disabilities and delays. Types of training by technical assistance requested by these program directors included:
 - 68% Workshops and training
 - 68% On-site technical assistance
 - 51% Materials for classroom use
 - 44% Additional staff
 - 41% Written/audio-visual materials

Children with Mild Developmental Delays

- 37% of child care programs serve children with mild developmental delays.
- Child care programs typically monitor the child's development and/or refer for other services:
 - 90% Monitor child's development
 - 43% Refer for screening and evaluation
 - 20% Refer to community prevention program
 - 13% Refer for therapy services
 - 20% Offer a home program
 - 6% No plan for these children
- 66% of child care programs report that their community does not have enough services for children with mild delays.

Child Care Providers' Perspectives: Infant Mental Health Survey

- Survey response rate (number of surveys mailed/returned)
38% (75/195)
- 12% of infants/toddlers in child care programs were identified by child care providers as having social/emotional concerns.
- In child care programs, there was a range in the intensity of concerns identified.
 - 62% Mild concerns
Ongoing difficulties responding to regular program services
 - 27% Moderate concerns
Serious difficulties requiring some additional intervention assistance
 - 7% Severe concerns
Require urgent attention
- 42% of child care programs have had to ask a family to withdraw their child due to social/emotional concerns.
- The most frequent reason for asking a family to withdraw a child was biting. Other reasons included hitting, aggression and being harmful to others.
- Moderate percentages of programs reported family mental health concerns, including:
 - 47% Chemical dependency
 - 42% Troubled parent/child relationships
 - 41% Domestic violence
 - 40% Child abuse/neglect
 - 33% Depression
 - 20% Other mental health concerns
- Programs reported that family social/emotional concerns were most difficult for staff.
- Programs meet social/emotional/mental health needs primarily through referral to outside agencies for additional services and their regular staff.
 - 75% Refer to outside agencies
 - 63% Rely on regular staff
 - 31% Use mental health consultants
 - 25% Use staff with special training
- 56% of child care programs have staff with special training or consultants in mental health/social/emotional development.
- 29% of child care programs report using mental health staff consultation.
- These specialists provide child (27%) and family (15%) assessment.

- 69% of child care programs that do not have mental health consultation would like to have such a service.
- 88% of child care programs reported that they make mental health referrals. Referrals are made to:
 - 47% Community Mental Health Centers
 - 40% School districts
 - 37% Child and Family Connections
 - 19% Private providers
 - 16% Medical or hospital programs
- Child care programs reported that a range of mental health services is available in most communities.
 - 67% Diagnostic evaluation
 - 65% Parent counseling/psychotherapy
 - 65% Individual child therapy
 - 60% Parent/child psychotherapy
 - 52% Mental health consultation
 - 8% Therapeutic nursery
- Although most child care programs surveyed reported that the amount of services in their communities is about adequate to meet the social/emotional needs of the children they serve, a significant minority did not find this to be so.
 - 43% No, not adequate to meet needs
 - 57% Yes, adequate to meet needs
- Training in social/emotional/mental health is a moderate to high priority for the staff of these programs.
 - 30% High priority
 - 53% Moderate priority
 - 18% Low priority
- The following types of trainings would be most useful:
 - 84% Identifying social/emotional/mental health concerns in infants/toddlers
 - 64% Initiating discussion with families about child concerns
 - 45% Working with families around concerns about child behavior/social/emotional/mental health
 - 23% Identifying social/emotional/mental health concerns in parents
- Only 32% of programs reported that they feel prepared or very prepared to meet the social/emotional needs of infants, toddlers, and families.
 - 4% Very prepared
 - 28% Prepared
 - 52% Somewhat prepared
 - 14% Not prepared
 - 3% Not at all prepared

- Child care programs surveyed were asked to report one change/addition that would better prepare them to meet social/emotional needs. The responses were:
 - More training
 - Additional staff/consultants with training in mental health
 - Expanded/adapted services
- When asked what were the greatest unmet needs in their communities regarding social/emotional concerns, the providers reported:
 - Availability of mental health services
 - Availability of trained therapists for infants and toddlers
 - Funding for infant mental health services

Child Care Providers' Perspectives: Child Care Developmental Screening Survey Findings

- Survey response rate (number of surveys mailed/returned)
44% (89/200 total)
- Screenings are generally a part of childcare programs.
 - 77% Provide/refer or arrange for screenings
 - 16% Do not provide, refer or arrange for screenings
 - 8% Other
- Child care programs reported that screenings are most frequently conducted by other agencies.
 - 52% Provided by other agencies
 - 36% off-site
 - 16% on-site
 - 25% Provided by childcare program
- Child care programs that conduct their own screenings typically screen all children. When other agencies screen, children are more likely to be screened only when there is a concern.
 - Childcare program
 - 81% screen all children
 - 10% screen only when a concern
 - Other agencies (on-site or off-site)
 - 27% screen all children
 - 64% screen only when there is a concern
- Child care programs screen both infants and toddlers; however, programs are most likely to screen children over one year of age.
 - 76% Birth-6 months
 - 88% 6-12 months
 - 94% 12-24 months
 - 97% 24-36 months
- Child care programs reported that screenings are typically held on-site.
 - 70% On-site
 - 16% On-site and off-site
 - 14% Off-site only
- Most child care programs screen children once a year or more.
 - 62% Once a year or more
 - 11% Every 2-3 months
 - 24% Every 6 months
 - 27% Once a year
 - 3% When enter program
 - 35% Other (when there is a concern)

- Child care programs report that nurses, program directors, and teachers conduct the screenings.
 - 52% Nurses
 - 25% Program directors
 - 17% Teachers
- The average number of infants and toddlers screened in a child care program is 34.
- Screenings in child care programs are picking up children who need further evaluation. 12% of children do not pass developmental screenings in child care programs

FOR PROGRAMS THAT DO THEIR OWN SCREENING

- Child care programs use a variety of information, relying most frequently on staff input, parent and staff observations of child, medical history, and use of a commercial tool. Almost half of the programs also use an agency-developed tool.
 - 100% Staff input
 - 95% Parent/caregiver observations
 - 95% Child interaction with peers/sibs
 - 70% Medical history
 - 65% Commercial screening tool
 - 53% Social/family history
 - 53% Observation parent-child interaction
 - 47% Agency screening tool
- The Denver is the most common commercial tool used in child care programs, followed by the Ages & Stages Questionnaire.
 - 18% Denver
 - 18% Denver II
 - 27% Ages & Stages Questionnaire
- The Denver (I&II) and Ages & Stages Questionnaire (ASQ) are seen by child care programs as reliable and valid; easy to administer (ASQ and Denver I), and affordable (ASQ & Denver II). Child care programs feel that evaluators are more likely to respect results of the Denver than the ASQ.
- Agency developed tools are seen by child care programs as the easiest to administer. They are also viewed as affordable, reliable and valid.
 - 88% Easy to administer
 - 55% Affordable
 - 44% Reliable and valid

- Child care programs reported that parents are typically not present for the screenings.
 - 55% Not present and provide no input
 - 14% Not present but provide input (questionnaire/phone)
 - 23% Present, observe, answer questions
 - 9% Present and assist

- Child care programs reported that follow-up is provided when a child fails the screening.
 - 86% Discuss concerns with family
 - 73% Observe
 - 64% Offer activities
 - 59% Refer for alternative screening/evaluation
 - 55% Screen again later
 - 41% Refer to Child & Family Connections (CFC—the entry point for state early intervention services)
 - 41% Consult with other professionals

- Child care programs refer most frequently to the school district for follow-up developmental evaluations.
 - 45% School district
 - 37% Child & Family Connections
 - 17% Hospital/medical provider
 - 13% Private provider
 - 16% Do not refer for evaluations

- 48% of child care programs report that they receive feedback on evaluations.

- Over half of the childcare programs have no knowledge of Child and Family Connections
 - 55% No knowledge
 - 15% Received written information about program
 - 13% Familiar, but have no written information

- In child care programs that do their own screening, if a child passes but there are still developmental concerns, follow-up is often provided.
 - 86% Discuss results with families
 - 68% Observe the child
 - 68% Offer activities to promote development
 - 64% Screen again later
 - 36% Consult with other professionals
 - 32% Refer to Child & Family Connections

- Children in child care often receive other health screenings.
 - 48% Vision
 - 44% Hearing
 - 23% Lead
 - 52% Iron

- Child care programs are more likely to reach out to other agencies for assistance in screening, than other agencies are to contact child care programs.
 - 65% Contact other programs to request screenings
 - 39% Contacted by other programs and offered screenings

- Early Intervention programs collaborate most frequently with child care programs to provide screenings.
 - 52% Early intervention programs
 - 29% School districts
 - 29% Public health programs
 - 23% Child and Family Connection sites

- Child care programs that arrange for others to do the screenings or who refer out are more satisfied with the screenings than programs whose staff conduct the screenings. However, they also know less about the screenings (tools used, who screens, how results are shared)

Program staff screening	Other
10%	40% Very satisfied
48%	30% Satisfied
43%	30% Somewhat satisfied

- 73% of child care programs are satisfied/very satisfied with screenings provided by other agencies.
 - Dissatisfaction comes from:
 - 19% Lack of feedback (feedback probably goes directly to parents)
 - 10% Waiting lists for screening services

- Child care programs reported the following strengths of their screening procedure:
 - Helps parents understand their child's needs
 - Screening is easy to do/interpret
 - Screeners have good training and experience
 - Screening is done on site (so convenient for staff and family)

- Child care programs reported the following weaknesses of their screening procedure:
 - Staff lack experience and training
 - Screening not done in a timely manner and done infrequently
 - Limited time or space to conduct screening

- Child care programs reported their greatest unmet needs regarding developmental screening and referral to be:
 - Poor knowledge of what services/resources exist
 - Lack of parent understanding of need for developmental screening- so limited follow through
 - Lack of training regarding screening tools and providing appropriate services
 - Poor turn around time getting screening conducted or getting results

Appendix B

Unmet Needs Project

Findings at a glance: Parents' Perspectives on Infant, Toddler, and Family Needs Beyond Part C Early Intervention Services in Illinois

Methods:

The Unmet Needs Project used two research methods, a mail survey and focus groups, to learn about the needs and experiences of families with children in early intervention programs.

Findings:

Early Intervention (EI) Parent Survey (The italicized statements in the following pages denote direct quotes.)

Nine early intervention programs, throughout the state of Illinois, agreed to distribute mail surveys to parents of children who received their services. Data was collected from January-December 1999.

The nine programs distributed surveys to 493 parents.

104 parents completed and returned surveys directly to the Unmet Needs Project. (21% response rate).

Early Intervention Parent Focus Groups

Two early intervention programs, one Child and Family Connection coordinator, and one parent liaison in different parts of the state of Illinois agreed to identify parents whose children had been in Early Intervention programs for at least six months and who would be willing and able to participate in a focused group discussion.

The following four focus groups were conducted:

Chicago	7 African-American mothers
Chicago	9 Latina mothers
Springfield	5 Caucasian mothers
Decatur	1 Latina and 9 Caucasian mothers and 1 Caucasian father

Both the EI program survey and the focus groups assessed parents' experiences related to non-required Part C services including medical care, respite care, recreation, and mental health. The results of the survey and the focus groups are presented together in this report by topic area.

Findings: Early Intervention (EI) Parent Survey and Parent Focus Groups

Age

Parent Survey

- The average age of child receiving EI services was 22 months (range: 1-37 months).

Transportation

Parent Survey

- The majority of parents reported that their child's EI program did not provide transportation for services.
 - 73% of respondents reported EI program did not provide transportation.
 - 27% of respondents reported EI program provided transportation.
 - 73% of parents receiving transportation were satisfied with the transportation being provided.

Health Care

Parent Survey

- 97% of survey respondents reported that their children have health insurance. Health insurance was of the following types:
 - 69% Private insurance from parent's work
 - 32% Medicaid (including KidCare and SSI)
 - 8% Division of Specialized Care for Children (DSCC)
- 92% of survey respondents reported that their children receive regular primary care (including baby shots, treatment for colds and ear infections, well baby check ups, etc.) at:
 - 92% Doctor's office
 - 7% Clinic setting
 - 3% Multiple clinics or hospitals
 - 1% Hospital emergency room
- 92% of respondents reported that their doctor understands their child's special needs.
 - Reasons doctor understands child's special needs included:
 - Doctor has special needs child of her own
 - Doctor specializes in child's disability
 - Child sees the same doctor at every visit
 - Reasons doctor may not understand child's special needs included:
 - Doctor is not specialized
 - Doctor lacks training

- Respondents reported that their children received care from the following types of specialists:
 - 41% Neurologist
 - 36% Ear, nose & throat specialist
 - 33% Ophthalmologist
 - 19% Behavioral & Developmental Pediatrics
 - 19% Orthopedist
 - 7% Psychiatrist/psychologist
 - 41% Others including cardiologist, geneticist, neurosurgeon, gastroenterologist, pulmonologist, endocrinologist, plastic surgeon, dentist, audiologist, hematologist, and nephrologist, allergist.
- 74% of parents reported not needing help with transportation to medical appointments. Of those parents who reported needing help:
 - 10% Reported needing vouchers for cab fares
 - 9% Reported needing paratransit or special transport services
 - 6% Reported needing vouchers for public transportation
- Problems related to medical care included:
 - 27% Determining the cause of their child's special needs
 - 25% Finding child care for other children in order to keep appointments
 - 24% Taking time off work for child's appointments
 - 23% Traveling to and from medical appointments
 - 16% Difficulty in determining what the child's special needs are
 - 13% Finding a medical specialist who understand their child's needs
 - 13% Lack of insurance reimbursement
 - 11% Obtaining needed equipment
 - 9% Finding sub-specialists within community
 - 7% Finding therapists who understand their child's needs

Focus Groups

- Parents want their pediatrician/family practitioner to listen to their developmental and behavioral concerns regarding their children and to let them know where they can get help.
 - Parents reported that physicians are missing early signs of developmental problems:

I just knew my child was not normal. And she [the physician] kept telling me you need to relax, you're tired... you're stressed, you're over reacting. Take his binky away, take the bottle away. I heard all of that and I just wanted to reach across the table and smack her. And say, you know what, none of this applies. He's not normal.

I trust my pediatrician to prescribe medicine. I trust them to check for pneumonia and ear infections and things like that, but as far as help for his developmental problems, I don't even ask him questions anymore.

I have an older child and I knew what was normal and I knew what was not normal and I fought with our doctor for over a year to give me a referral.

I went on my own and found EI.

- Physicians are not always addressing behavioral issues in a way that is helpful to families.

These doctors have no idea what it's like to live with a child; that any other person would be absolutely nuts living with these children.

It takes doctors in the area to acknowledge and not treat you like you're neurotic.

Let's wait until he's three. No, I'm not waiting. He's tearing up our house.

They (doctors) don't think outside the box at all. If they didn't learn it in medical school... they're not interested.

The amount of Ritalin my son was getting for his age [2 years] and size was three times the normal amount and it wasn't working.

- Families need services that may not be covered by their medical insurance.

My insurance doesn't cover speech pathology.

Insurance won't cover anything that's related to development of function, only restoration of function.

We have to fight for each doctor visit.

We had physical therapy covered to 100%, if we go about 300 miles from here.

I called and made sure this doctor [a psychologist] was covered and they have yet to pay. I had to stop taking him because it's \$100 every time you go.

- Parents whose physicians listened to and acted on their concerns were incredibly grateful.

I loved him.

He is superfantastic, I won't see another doctor.

He would do screenings on his own time with the children.

He actually listened to me.

Recreation

Parent Survey

- Parents reported that they would like their child to participate in the following community activities:

65% Infant/toddler play groups

48% Swimming

36% Religious practice

33% Gymnastics classes

15% Other activities including: horse back riding, animal interaction play group, infant massage, play in a handicapped accessible playground, reading, music or art group, go to malls and parties with family.

- The majority of parents reported that they are not aware of recreational activities for their children in their communities.
 - 64% Don't know of recreational activities
 - 15% Have not identified recreational activities
 - 14% Have identified recreational activities, including play groups, special recreation associations, swimming classes, park district programs, YMCA programs, and music groups.
- 84% of parents reported that their early intervention service coordinator had not talked with them about recreation services.
- Parents reported that children two years of age or older were getting enough support with social skill development from family members and through their early intervention (EI) program, but not in their general community.

	From family members	In the community	In child's EI program
Yes	87 %	45%	76%
No	13%	55%	24%

Focus Groups

- Parents believe recreation is important.
 - Recreation is important to socialize children and to help them learn.

There should be [recreation] for our kids too so that they can have the chance to go and do what other kids do

Our children's development gets promoted as they socialize with other children.

In spite of their disabilities, our children are very intelligent. The more we teach them, the more they are going to learn.
- Parents had mixed views of inclusion in recreation programs.
 - Some parents felt inclusion would benefit their children.

It is not good to isolate them into a group with [only children with] special needs. They should be integrated slowly into a regular class.
 - Some parents favored programs designed for children with special needs.

I think that services should be offered in a place where there are other children with special needs. Not all children are going to accept other children with special needs. Sometimes children can be very cruel.

- Parents reported many barriers to accessing recreational activities for their infants and toddlers including:
 - Lack of options- including nowhere to go, lack of equipment, and lack of trained staff

there's nothing [in our area] for children

I've never heard of anything, to be honest

There isn't equipment for them [at the local parks]. They do not have rubber tires... no swing to sit them in that you don't have to worry about them falling over.

they've got to have staff... not just equipment, but staff
 - Lack of information about options

I am also looking for different activities... I don't know where to take him.

We don't know where to find these activities

We don't know of places that offer these activities to children with special needs.
 - Prohibitive cost

...a lot of these things are a lot of money. My kids want to go sometimes and sometimes I just can't afford it... and you feel bad for them cause you can't afford it. And there's nothing you can do about it.
 - Lack of transportation options

I am tired of driving to this therapy and that therapy... I don't even have the energy to drive to let my child go swimming.

Maybe some of these activities are being offered at other places that are not close to our home. Transportation is a problem.

Social/Emotional and Behavioral Issues

Parent Survey

- Half of the parents surveyed reported behavior problems that they would like help in managing:
 - 16% Very short attention span
 - 15% Severe tantrums
 - 14% Discipline problems
 - 14% Hurting self
 - 13% Sleep problems
 - 12% Aggressive or acting out behavior
 - 11% Very high activity level
 - 11% Hurting others
 - 11% Feeding problems
 - 5% Other problems including insecurity, separation anxiety, withdrawal.

- Of those parents who reported behavioral concerns, 11% reported that they have not received help with their concerns.
- Parents who reported receiving help for behavior concerns received it from the following:
 - 32% Early Intervention (EI) program
 - 24% Family members
 - 21% Child's doctor
 - 14% Friends
 - 2% Psychologist not associated with EI program
 - 1% Special clinic or program specifically for behavior problems
 - 9% Other medical specialist including developmental doctor, neurosurgeon, neurologist, home care nurse, nutritionist.
 - 9% Other specialist including developmental, occupational, speech, and physical therapists, behavioral therapist, case worker, support group, foster agency staff, reading books.
- Within EI programs, parents reported that the following people have been most helpful with behavioral concerns:
 - 35% Speech and Language Therapist
 - 30% Physical Therapist
 - 28% Occupational Therapist
 - 26% Developmental Specialist
 - 5% Behavior Therapist or Interventionist
- 9% of parents reported that their behavioral concerns have not been addressed within their EI program.
- Several parents reported that they have concerns about their relationship with their child with which they would like help. Parents reported the following:
 - 5% My own worries make it hard to respond to my child
 - 4% My child doesn't respond to parent as he/she should
 - 3% My child is difficult to calm or comfort
 - 2% I usually do not enjoy time with my child
 - 10% Other responses included: child is overly dependent, demanding; severe separation anxiety
- Parents who have relationship concerns reported receiving help from the following:
 - 16% Family and friends
 - 15% Child's early intervention program
 - 9% Child's doctor
 - 2% Psychologist not associated with EI program
 - 1% Psychiatrist
- 20% of parents with relationship concerns reported that they have not received help with these concerns.

- Almost half of parents surveyed reported that they feel that counseling services would help them in caring for their child.
 - 47% Yes. Specifically family counseling, individual therapy, parent support, stress management, parenting classes, and financial planning for special needs children.
 - 53% No
- 13% of parents reported that they had already received counseling (i.e., family counseling, parents' group, individual counseling, or through an early intervention program).

Focus Groups

- Parents reported a high degree of stress:
 - The time and energy needed to manage child's services and be child's advocate can be overwhelming.
 - Your life's not your life anymore.*
 - You get therapied out.*
 - ...there's a depression and anxiety level that just makes you not be able to reach out and go any further.*
 - The stress of managing work on top of family/child responsibilities is great.
 - Sometimes you just feel like you're in a spin cycle. You need the money, you need the job...but you've just got too much to handle.*
 - I had to give up a really good job or be terminated from my job because they felt like my family conditions were too much for me to handle at the level I was at.*
 - Stress spills over into the marriage and into the relationship with the child.
 - We are still married but we were almost divorced because I felt like I'm doing everything—you're doing nothing—and there was nobody to talk to about that.*
 - Sometimes we feel trapped and we are not very patient with our children. We fail in being positive and optimistic and we project this onto our children.*
- Parents expressed a need for emotional support in everyday encounters.
 - When the service coordinator calls, I don't get 'Hi, how are you?' Instead, she focuses on services Okay, what do we have to do for Rachel now?*
 - There needs to be someone out there saying: 'you know what, you're doing a good job.' ' You are okay' ...encouragement...telling you don't lose your dream for your kids.*
 - You could read what ever you want off the internet but it's not like talking to somebody.*
 - For two years, their father enjoyed the children. My job was to be on top of things, not to play with someone. You know, your role changes and nobody is there to talk about it.*

- Parents wanted professional counseling.

If our children have specific therapies, we also have the need for support. We need someone to provide therapy to us. We as parents get tired, frustrated. Sometimes, we don't know what to do. We need to have support, a moment when we can sit and talk and get some of this pressure off. We need more of these [parent groups]. We really need someone that can tell us what to do at times—someone that can comfort us and encourage us.

We need guidance in how to help our older children. My older son is constantly asking me why his brother does not walk. It's difficult to explain this. What I usually end up doing is locking myself in the closet and crying. This, in my view, is the result of not having enough support and help... If we don't get the proper support, we take it out on our children.

The information from the service providers was making a wedge between [my husband and me]... somewhere along there, [I wish that] some type of counseling would've been offered to try to pull us together... I finally went to my doctor and said 'medicate me'... but that wasn't fixing the problem.

- Parents expressed a need for support from other parents.
- In all four focus groups, parents expressed a desire to meet with other parents in parent groups. In one group, parents wished that parent group participation was a requirement as it had been in the past.

I miss that [family group]. I miss having to come here and talk and give your opinion... telling how you feel... have someone to help you with how you are feeling. I looked forward to that.

Child care will be needed: How good is a support group if I can't go with my husband?

- Parents expressed a need for parent counseling around child behavior issues.
- Parents reported great distress over a range of child behavior concerns including sleep problems, head banging, weaning from bottle, tantrums, inconsolable crying, escaping, turning over furniture, hitting, risk-taking behavior

Sleep problems: It's torture. You're like the walking dead.

Risk-behavior: He's a constant threat to his safety.

High activity: I constantly need to supervise him. If he gets hurt, I could be blamed of neglecting him.

- Family activities were limited by difficult child behavior.

We don't take our 2 year old out any more because I'm so tired of that 'lady get your kid under control' or they give you that look"

- Parents also reported that many of the recommendations they had previously received from professionals were not helpful. However, parents also reported that most of the behavior management strategies parents used were not working: timeouts, spanking, 1-2-3 method. Parents reported wanting help from professionals experienced and knowledgeable about behavior problems in children with special needs.

I would have been interested in that (counseling on child behavior) and I still would because last night I lost my temper with my son... And that makes me feel terrible....And I'm like crying for two hours. What do you do?

- The parents reported receiving little, if any, information about social/emotional support as part of Part C Plans.
- Only one parent reported receiving psychological services. Other parents reported that they were not offered social work or psychological services. Several parents said that when it was brought up, it was not explained very clearly. Some assumed that the support person would be the service coordinator.

We need a social worker or someone that is qualified to talk to parents to guide us and to guide our children.

Every parent should have a chance and be offered this service.

Respite Care

Parent Survey

- Parents reported that the following people take care of their child when they simply need a break, need to run errands, or go to their own doctor's appointment.
 - 74% Family
 - 22% Babysitter
 - 20% Friends
 - 6% Respite worker
- 12% of parents reported that no one is available to help them when they need a break.
- The majority of parents (60%) reported that no one had told them about respite care.
- Those parents who reported knowing about respite care had learned of respite from agency staff, friends, therapist, family, prior experience, guardian, and their insurance.
- 68% of parents who knew about respite services had not used them.
- Families who were using respite services reported being very satisfied with the service.
 - 52% Very satisfied
 - 26% Satisfied
 - 6% Somewhat satisfied
 - 6% Not satisfied
 - 10% Not at all satisfied

- Satisfaction with the amount of respite time that was available to families varied widely.
 - 38% Very satisfied
 - 17% Satisfied
 - 21% Somewhat satisfied
 - 0% Not satisfied
 - 24% Not at all satisfied

- The majority of parents reported being very satisfied with the quality of their respite care workers.
 - 75% Very satisfied
 - 10% Satisfied
 - 5% Somewhat satisfied
 - 0% Not satisfied
 - 10% Not at all satisfied

- Half of the parents who know about respite care reported that they had difficulty finding respite care services.
 - 51% Yes
 - 49% No

- Home-based respite care was the most common type of respite used by parent respondents.
 - 76% Home based
 - 16% Center based
 - 8% Caregiver in community

- Home-based respite was also the preferred type of respite for parent respondents.
 - 85% Home based
 - 11% Center based
 - 5% Caregiver in community

- Almost half of parents surveyed (42%) reported that they had needed respite care for an emergency. Of these, 79% reported that they had not been able to find services.

Focus Groups

- Parents are unaware that respite care service exists.
- A large number of parents who participated in our focus groups were not aware that respite care exists.

So respite care is something that's used to give parents a break?

I've been in the system since my [2 year old] grandson was nine months old and I've never heard of any of this.

- Parents expressed a great need for support.
- Parents reported that they are overwhelmed and need support.

I need it, but I don't have extra money to pay for [respite].

My child has multiple needs, multiple appointments and it is very hard to do all of these. With respite I feel supported. I can call [my worker] whenever I need to.

- Respite care helps ensure child's safety.

[Without respite] everything is difficult for me. My child is very active... [he] needs a lot of individual attention. I constantly need to supervise him so he doesn't fall and hurt himself. It is very tiring to do this all the time.

- Respite care helps ensure family members' well-being.

If I didn't have this service it would be very hard for me to cope... Sometimes I feel very depressed and that's when I need a lot of help. If I didn't have someone to take care of my child at these moments, I would probably feel desperate and helpless. I don't know what I would do without this service. Thanks to God that I have it.

I use this service so I can attend to the needs of my other children.

- Respite care service is hard to access.
- Accessing respite services depends on where parents live.

I live very far away [and have not been able to get respite]. I have missed many appointments, I haven't been able to take care of my own health.

- Parents reported using different sources and types of respite care.
- Many parents use family members or friends for respite, but at a price.

I might get my mom [to watch my child] for three hours because my mom isn't an old woman—or a sister, but I still have to pay them. Whoever I find, I have to pay them... So I often don't go.

My problem is that someone would [watch our kids] one time and then never want to again... It's too much work. So, as a parent, you don't do things, you don't go out to movies, you don't go to dinner, you don't go over to friends' houses for dinner. Everything stops.

My mom watches our son a lot of the time because we both work... She's 61 and she's in great shape and everything, but you know, you feel guilty saying, even though she offers, would you keep him for the night so we can go to a movie... I feel like we're taking advantage.

- Different forms of respite care serve different needs.
 - When asked about different forms of respite care, parents had mixed evaluations of home- and center-based respite care.

Home-based care:

Someone comes to my home to help me with my child.

When we have appointments, the respite worker can accompany us.

"I would rather drop [my child] off. Nobody comes into my house to tell me how to do things.

Center-based care:

You might want to go out for a couple hours or come home and rest.

You need a way to get there. It can be far away... So if you can't get there, then no respite.

My son would rip it up and cry until he would make himself sick, because it would be a change.

Nontraditional Therapies or Treatments

Parent Survey

- 45% of parents surveyed reported that they had used nontraditional therapies or treatments
- Parents reported using the following types of therapies or treatments
 - 19% Infant massage
 - 7% Multivitamins
 - 2% Chiropractic
 - 1% Homeopathy
 - 5% Other treatments mentioned as being nontraditional included: brushing, gluten and casein free diet, music, prayer, sensory integration therapy.
- 1% reported that they had not found non-traditional therapies useful.

Appendix C

Unmet Needs Project

Findings at a glance: Developmental Screening of Infants and Toddlers in Illinois

Developmental Screening² by Primary Care Physicians

- Survey response rates (number of surveys mailed/returned)
30% (128/429) Pediatricians
18% (65/361) Family Practitioners
3% (6/183) General Practitioners³
20% (199/973) Total
- The average number of children in a physician's practice was 1244.
(Range=2-6000)
- Surveys were mailed and data collected between December 1999 and November 2000.
- The vast majority of physicians (92%) reported that they provide developmental monitoring⁴.
- Most physicians report that they monitor the development of all children.
92% Pediatricians
78% Family practitioners
- 87% of physicians monitor development at each Well Child visit.
- Typically, it is the physician who monitors the child's development.
89% Reported that MDs monitor development
29% Reported that nurses monitor development
8% Reported that others monitor development
- Despite physicians reporting that they are providing developmental monitoring, 64% of physicians surveyed are not using commercially developed screening tools.
- Of the 36% of physicians who use commercially developed screening tools, the Denver and Denver II were the most common tools, followed by the Ages & Stages Questionnaire.

² A developmental screening is a brief procedure designed to identify children who may have a developmental delay or developmental disability and require further evaluation. Screenings can include the areas of cognition, communication, motor, social/emotional, self help, problem solving or general development (combining these areas). The screening may rely on clinical judgment, a commercially available instrument, an agency developed tool, or a combination of methods.

³ Results are not reported for general practitioners because of the extremely low number of responses.

⁴ Developmental monitoring includes asking general, nonstandardized questions regarding development and behavior, and conducting observations of parent and child.

- Emotional and behavioral development is less frequently screened for than other domains of development. The areas of development physicians reported screening were:
 - 91% Communication
 - 89% Motor
 - 82% Cognitive
 - 81% Social
 - 69% Emotional/Behavioral

- Developmental screenings are identifying children who need further evaluation. However, the average rate of children identified through screenings differed by physician specialty.
 - Pediatricians - 10% of children fail screenings
 - Family Practitioners- 3% of children fail screenings

- Physicians reported the following barriers to screening/monitoring:
 - 75% Limited time
 - 78% Pediatricians
 - 71% Family practitioners

 - 36% Lack of staff
 - 39% Pediatricians
 - 31% Family practitioners

 - 34% Lack of financial reimbursement
 - 40% Pediatricians
 - 25% Family practitioners

 - 27% Lack of parent acceptance of delay
 - 14% Family practice
 - 34% Pediatricians

 - 23% Lack of training
 - 23% Family practice
 - 23% Pediatricians

- If a child passes a screening, but the physician has concerns regarding development, follow-up is often provided.
 - 81% Discuss concerns with family
 - 86% Pediatricians
 - 72% Family practitioners

 - 54% Offer suggestions to promote development
 - 62% Pediatricians
 - 40% Family practitioners

 - 52% Refer for alternative screening/diagnostic evaluations
 - 54% Pediatricians
 - 52% Family practitioners

- 31% Refer to Help Me Grow/Child and Family Connections
 - 42% Pediatricians
 - 9% Family practitioners
- If a child fails a screening, physicians are most likely to discuss concerns with families and refer for an alternative assessment
 - 67% Discuss concerns with family
 - 72% Pediatricians
 - 57% Family practitioners
 - 67% Refer for alternative evaluation/screening
 - 66% Pediatricians
 - 70% Family practitioners
 - 35% Offer activities to promote development
 - 42% Pediatricians
 - 23% Family practice
 - 29% Refer to Help Me Grow/Child and Family Connections
 - 39% Pediatricians
 - 9% Family practice
- Generally, physicians refer children with behavioral or social/emotional concerns to mental health services.
 - 87% Pediatricians
 - 60% Family practice
- Physicians most frequently refer children to private providers and medical centers for developmental evaluations.
 - Child and Family Connections
 - 5% Family practice
 - 36% Pediatricians
 - School districts
 - 11% Family practice
 - 22% Pediatricians
 - Medical Centers
 - 28% Family practice
 - 36% Pediatricians
 - Private providers
 - 23% Family practice
 - 49% Pediatricians

- 34% of physicians surveyed had no knowledge of the Child and Family Connections (CFCs).
 Pediatricians were three times more likely to know about the CFC's than family physicians.
 - 20% Pediatricians
 - 62% Family practice

- Physicians reported the following barriers to referring a child with a delay or disability for evaluation:
 - 54% Length of time for evaluations to be done
 - 59% Pediatricians
 - 41% Family practice
 - 44% Families not following through with the referral
 - 47% Pediatricians
 - 35% Family practice
 - 37% Limited number of programs
 - 35% Pediatricians
 - 39% Family practice
 - 32% Not having enough information about evaluation programs
 - 25% Pediatricians
 - 45% Family practice

- Physicians overwhelmingly reported that they believe that early intervention is effective for infants and toddlers with:
 - 98% Mild delays
 - 98% Pediatricians
 - 97% Family practitioners
 - 98% Physical disabilities
 - 98% Pediatricians
 - 97% Family practitioners
 - 96% Mental retardation
 - 97% Pediatricians
 - 95% Family practitioners
 - 94% Communication/social-relatedness disabilities
 - 97% Pediatricians
 - 91% Family practitioners

- The greatest unmet needs reported by physicians regarding the system of birth to three screening, evaluation and services for developmental issues included:
 - Availability and affordability of services
 - Availability of bilingual services
 - Lack of services for children with pervasive developmental disorders and mental health issues

Developmental Screening in Prevention Programs

- Survey response rates (number of surveys mailed/returned)

75% (51/68)	Prevention Initiative
71% (15/21)	Early Head Start
54% (15/28)	Healthy Families
53% (60/114)	Parenting Training
47% (9/19)	Parents too Soon
40% (2/5)	Family Focus
58% (148/255)	Total
- Screenings are a part of prevention services.

94%	Programs provide/arrange screenings
57%	Programs provide the screenings themselves
- Screenings take place in a range of settings. Most programs offer screening in the home and at the program.

51%	Home and program
36%	Home
8%	Program site
- Children in prevention programs are typically screened once a year or more.

35%	Once a year
30%	Every 6 months
14%	Every 2-3 months
4%	Once during the birth to three years
18%	Other
- Prevention programs report that parents are typically present and often assist with the screenings in prevention programs.

57%	Parents are present, answer questions and assist in screening
50%	Parents are present, answer questions and observe
5%	Parents are not present but fill out a questionnaire
1%	Parents are not present and they do not provide input
- Denver is the most frequently used tool in prevention programs.

38%	Denver II
26%	Ages & Stages Questionnaire
22%	Denver Developmental Screening Test
6%	Battelle Screening Test
- Developmental Specialists/Home Visitors are the most commonly used screeners.

45%	Home Visitor
43%	Child Development Specialist
27%	Program Director

- Screenings are identifying children who need further evaluation.
 - 13% Children fail developmental screenings in prevention programs
- Prevention programs refer children for developmental evaluations to:
 - 72% Child and Family Connections
 - 29% School districts
 - 18% Hospitals
- Prevention programs follow-up on children who pass screenings but for whom there are still concerns in various ways.
 - 69% Screen again later
 - 68% Discuss concerns with family
 - 62% Observe child's development
 - 56% Consult with professionals
- Prevention programs are generally satisfied with their screening procedures.
 - 34% Very Satisfied
 - 53% Satisfied
 - 13% Somewhat Satisfied
 - 0% Dissatisfied
 - 0% Very Dissatisfied
- Prevention programs reported the following strengths of the screening procedure used:
 - 29% Ease of administration of tool
 - 13% Qualified staff
 - 11% Family-friendly
- Prevention programs reported the following weaknesses of the screening procedure used:
 - 21% Accuracy/validity/reliability
 - 20% Staffing issues
 - 15% Concerns about parent involvement
- The greatest unmet needs reported by prevention programs regarding developmental screening were:

The limited outreach to families about availability and importance of screenings, referrals, and services

Limited services, especially specialty services such as occupational therapy, physical therapy and speech therapy, and bilingual services and staff

Transportation

Developmental Screening in Early Intervention (EI) Programs

- Survey response rate (number of surveys mailed/returned)
76% (61/80)
- Screenings are part of Early Intervention (EI) services.
92% EI programs provide screenings
- EI programs reported that screenings take place in a range of settings.
 - 56% Child care
 - 48% Public schools
 - 36% Churches
 - 29% Preschools
 - 26% Public health
 - 15% Libraries
 - 13% Early Head Start
 - 6% Program site
 - 38% Other (homes)
- EI programs publicize their screenings primarily through word of mouth, posters/flyers, and CFCs.
 - 76% Word of mouth
 - 74% Flyers/posters
 - 74% CFCs
 - 55% Newspapers
 - 48% School bulletins
 - 31% Radios
 - 18% Other (e.g., health fairs)
- EI programs reported that parents are typically present and often assist with the screenings.
 - 70% Parents are present, answer questions and assist in screening
 - 54% Parents are present, answer questions and observe
 - 12% Parents are not present, but fill out a questionnaire
 - 5% Parents are not present and provide no input
- The Denver is the most frequently used tool in EI programs.
 - 29% Denver II
 - 21% Denver Developmental Screening Test
 - 17% Battelle Screening Test
 - 10% Ages & Stages Questionnaire
- Developmental specialists/home visitors are the most commonly used screeners in EI programs.
 - 87% Child Development Specialist/Early Educator
 - 65% Program Director

- Specialists are often involved in screenings in EI program settings.
 - 28% Nurse
 - 28% Service Coordinator
 - 23% Speech/Language Pathologist
 - 19% Occupational Therapist
 - 15% Physical Therapist
- EI programs follow-up on children who pass screenings but for whom there is still concern.
 - 87% Discuss concerns with family
 - 71% Screen again later
 - 48% Refer to Child and Family Connections
 - 24% Refer to prevention programs
- EI programs are generally satisfied with their screening procedures.
 - 39% Very Satisfied
 - 44% Satisfied
 - 17% Somewhat Satisfied
 - 0% Dissatisfied
 - 0% Very Dissatisfied
- EI programs reported the following strengths of the screening procedure used:
 - 17% Qualified staff
 - 16% Family-friendly
 - 13% Ease of administration
- EI programs reported the following weaknesses of the screening procedure used:
 - 18% Accuracy/validity/reliability
 - 14% Staffing issues
 - 12% Adequate number of screenings
 - 12% Outreach/public awareness
- The greatest unmet needs reported by EI staff regarding developmental screening were:
 - Limited services, especially specialty (occupational therapy, physical therapy, and speech therapy) and bilingual services and staff
 - Collaboration among agencies and professionals; goal of increased physician knowledge of services and referrals
 - Public awareness of Child Find*
 - Funding for screenings

* Public relations activities that communicate the need for and availability of developmental screening and EI services to the community, especially to parents.

Child and Family Connections (CFCs) Developmental Screenings through Local Interagency Council (LIC) Outreach Efforts

- Survey response rate (number of surveys mailed/returned)
71% (17/24)
- CFCs are providing developmental screening through Local Interagency Council (LIC) Outreach Efforts.
CFCs screened an average of 800 children in 1999
- Children are being screened across the birth to three-year age range.
 - 88% Birth to 6 months
 - 88% 6-12 months
 - 88% 12-24 months
 - 88% 24-36 months
- CFCs are collaborating with many programs in providing the screenings. Most frequent collaborations include EI programs, School Districts, Public Health Clinics, and Child care Settings.
 - 88% Early Intervention program
 - 82% School District/Board of Education
 - 65% Public health clinic
 - 65% Child care setting
 - 47% Preschool program
 - 35% Early Head Start program
 - 29% Parental training program
 - 24% Prevention Initiative program
- CFCs are screening at a range of sites including public health clinics, daycare programs, public schools and preschool programs.
 - 77% Public health clinic
 - 77% Child care setting
 - 65% Public school
 - 59% Other
 - 53% Preschool program
 - 41% Early Head Start program
 - 41% Church
 - 24% Library
- CFCs advertise the screenings in a range of different ways including:
 - 82% Word of Mouth
 - 82% Posters/Flyers
 - 82% School Bulletins
 - 53% Newspaper
 - 24% Radio
 - 24% Other
 - 12% Internet
 - 12% Television

- The primary screening tools used by CFCs include Denver and Ages & Stages Questionnaire.
 - 47% Ages & Stages Questionnaire
 - 47% Denver Developmental Screening Test
 - 41% Denver II
 - 12% Battelle Screening Test
 - 6% Hawaii Early Learning Profile
- CFCs reported that the two most frequently identified strengths of tools used were ease of administration and affordability.
 - 82% Easy to administer
 - 77% Affordable for programs
 - 59% Good reliability and validity
 - 53% Accurate assessment of developmental level
 - 53% Evaluators respect results
 - 35% Available in other languages
 - 30% Culturally appropriate for population
 - 12% Other
- The vast majority of CFCs reported that parents are involved in the screening procedure.
 - 71% Parents are present, answer questions and observe the screening
 - 47% Parents are present, answer questions and assist in screening
 - 12% Parents are not present but fill out a questionnaire or answer questions
 - 12% Parents are not present and they do not provide input
- CFCs follow-up on children who pass screenings but for whom there is still concern.
 - 83% Screen again later
 - 77% Discuss concerns with family
 - 53% Refer to Child and Family Connections
 - 41% Refer to Prevention Program
 - 12% Offer Home Program to Parents
 - 6% Refer for evaluation through alternative to Child and Family Connections
- CFCs are generally satisfied with their screening procedure.
 - 24% Very satisfied
 - 41% Satisfied
 - 24% Somewhat Satisfied
 - 0% Dissatisfied
 - 0% Very Dissatisfied
- CFCs reported that the main strength of the developmental screening procedure used was:
 - Good collaboration with other programs in conducting screenings
- CFCs reported that the main weaknesses of the developmental screening procedure used were:
 - Need for more availability of screenings and better outreach
 - Inadequate funds to carry out screenings.

- CFCs reported that their greatest unmet needs regarding developmental screening were:
 - Need more services such as vision, hearing and assistive technology
 - Need specialized therapists
 - Greater Outreach, Child Find, and public relations

Developmental Screenings offered through Public Health Clinics

- Survey response rate (number of surveys mailed/returned)
86% (85/99)
- Public health clinics provide developmental screening through Family Case Management; Women's, Infants' and Children's Program; and Well Child Clinics.
Public Health Clinic Programs screened an average of 510 children in 1999
- Public health clinics reported that children are screened from birth to three years, but screenings decrease during the 2-3 year age range.
 - 95% Birth to 6 months
 - 98% 6-12 months
 - 90% 12-24 months
 - 77% 24-36 months
- Public health programs reported that developmental screening is provided most frequently through Family Case Management* (FCM) and WIC (Women, Infants and Children Supplemental Food Programs).
 - 89% Family Case Management
 - 63% WIC
 - 37% Well Child Clinic
 - 36% Other: High-risk birth registry, Healthy Families, and High Risk Follow-Up
- Public health programs reported that screenings are provided both at home and on-site.
 - 84% Home & clinic site
 - 10% Clinic site
 - 5% Child's home
- The primary screening tool used in Public Health Programs is the Denver.
 - 44% Denver II
 - 36% Denver Developmental Screening Test
 - 8% Agency developed screening tool
 - 3% Battelle Screening Test
 - 2% Ages & Stages Questionnaire
- Public health programs reported that the primary strengths of the screening tool include ease of administration and affordability.
 - 92% Easy to administer
 - 71% Affordable for programs
 - 60% Good reliability and validity
 - 58% Accurate assessment of developmental level
 - 55% Evaluators respect results
 - 31% Culturally appropriate for population
 - 5% In other languages than English

* Family Case management programs in Chicago are separate from the Public Health clinics. The Chicago data on Family Case Management is reported on page 71.

- 100% of public health programs reported that parents are involved in the screening procedure.
 - 49% Parents are present, answer questions and observe
 - 51% Parents are present, answer questions and assist in screening
- Following the screening, if there are still concerns, public health professionals:
 - 82% Discuss concerns with family
 - 76% Screen again later
 - 66% Observe child's development
 - 65% Refer to Child and Family Connections
 - 52% Consult with other professionals
 - 32% Refer for evaluation as alternative Child and Family Connections
 - 10% Offer a home program to Parents
- Public health clinic programs are satisfied with their screening procedure.
 - 26% Very satisfied
 - 47% Satisfied
 - 10% Somewhat Satisfied
 - 2% Dissatisfied
 - 0% Very Dissatisfied
- Public health programs reported that the main strengths of the screening procedure used were:
 - Tool is easy to administer
 - Procedure allows for early identification of delays
- Public health programs reported that the main weaknesses of the screening procedure used were:
 - Too time consuming
 - Tool is too basic (not providing sufficient information)
 - Difficult to engage child in the screening
- Public health programs reported their greatest unmet needs regarding developmental screening:
 - Lack of sufficient programs/services
 - Lack of programs for infants and toddlers at-risk and with mild delays
 - Lack of agency coordination and communication (within & between)
 - Lack of transportation options

Developmental Screening through Chicago Family Case Management Programs (FCM)

- Survey response rate (number of surveys mailed/returned)
55% (21/38) Total
- The vast majority of FCM programs either provide developmental screening or arrange for developmental screening to be conducted by others.
 - 52% Provide screening themselves
 - 33% Arrange for others to provide screening
 - 5% Provide or arrange for screening
- Family case management programs in Chicago reported that the majority of children are screened during their first year of life.
 - 48% Birth to 6 months
 - 52% 6 to 12 months
 - 5% 12 to 24 months
 - 10% 24 to 36 months
- Most of the family case management programs surveyed reported that they screen children every 2 to 3 months.
- Family case management programs in Chicago reported that screenings take place both in children's homes and at the agency site.
 - 10% Child's home
 - 10% Agency site
 - 38% Both child's home and agency site
- Screenings are most often conducted by case managers, nurses, social workers in family case management programs
 - 52% Case managers
 - 24% Nurses
 - 10% Social workers
 - 5% Child development specialist
 - 5% Physician
 - 5% Family specialist
 - 5% Home visitors
- These family case management programs reported that Ages & Stages is the most frequently used screening tool, followed by agency-developed tools.
 - 52% Ages & Stages Questionnaire
 - 24% Agency-developed screening tool
 - 14% Denver Developmental Screening Test
 - 5% Child Development Inventories

- Family case management programs in Chicago reported that the strengths of their screening procedure are ease of administration, accuracy of assessment, and affordability.
 - 48% Easy to administer
 - 33% Accurate assessment
 - 33% Affordable
 - 29% Culturally appropriate for population
 - 14% Evaluators respect results of tool
 - 10% Valid and reliable
 - 10% Available in languages other than English
- These family case management programs reported that parents participate in screening.
 - 47% Parents are present, answer questions and observe
 - 29% Parents are present, answer questions and assist in screening
- Family case management programs in Chicago reported that screening results are not always reported to others.
 - 48% Report to parents
 - 14% Report to physicians
 - 5% Report to a social service agency
- If a child passes the screening, but there are still concerns regarding development, family case management staff:
 - 38% Consult with other professionals
 - 33% Refer for alternative screening/developmental evaluation
 - 24% Observe the child's development
 - 24% Discuss concerns with family
 - 23% Refer to Child and Family Connections
 - 14% Screen again later
 - 5% Offer home program to parents/caregivers
- In general, family case management providers were moderately satisfied with their developmental screening procedure:
 - 0% Very satisfied
 - 58% Satisfied
 - 33% Somewhat satisfied
 - 8% Dissatisfied
 - 0% Very dissatisfied
- Infants and toddlers received other screenings as a result of family case management programs:
 - 85% Lead
 - 82% Iron
 - 77% Vision
 - 75% Hearing

- Family case management programs in Chicago that arrange for others to provide developmental screening most often reported using medical or early intervention providers.
 - 62% Medical/hospital providers
 - 57% EI providers
 - 38% Board of Education/School District
 - 38% Child and Family Connections
 - 10% Department of Children and Family Services
- In general, family case management programs in Chicago reported being satisfied with the screenings provided by other agencies.
 - 12% Very satisfied
 - 59% Satisfied
 - 24% Somewhat satisfied
 - 6% Dissatisfied
 - 0% Very dissatisfied
- Family case management providers who were dissatisfied with screenings provided by others identified lack of availability of screenings, lack of feedback regarding screening results, and waiting lists for screening as reasons for their dissatisfaction.
- These family case management programs most frequently refer children to medical providers for developmental evaluations. Sites of referral included:
 - 52% Medical/hospital program
 - 38% Child and Family Connections
 - 33% School district
 - 24% Private provider
- When family case management programs receive results of developmental evaluations, they are most often in the form of a written report. Several programs reported that they do not receive feedback.
 - 52% Written report
 - 33% Verbal report
 - 14% Do not receive feedback
- Chicago Family case management programs reported the following approaches to the referral/management of infants and toddlers with mild delays who are ineligible for part C early intervention services.
 - 57% Refer to prevention programs
 - 52% Refer for further screening or evaluation
 - 52% Monitor development
 - 24% Refer for therapy services
 - 19% Offer home programs to promote development

Child Care Providers' Perspectives: Child Care Developmental Screening Survey Findings

- Survey response rate (number of surveys mailed/returned)
44% (89/200 total)
- Screenings are generally a part of childcare programs.
 - 77% Provide/refer or arrange for screenings
 - 16% Do not provide, refer or arrange for screenings
 - 8% Other
- Child care programs reported that screenings are most frequently conducted by other agencies.
 - 52% Provided by other agencies
 - 36% off-site
 - 16% on-site
 - 25% Provided by childcare program
- Child care programs that conduct their own screenings typically screen all children. When other agencies screen, children are more likely to be screened only when there is a concern.
 - Childcare program
 - 81% screen all children
 - 10% screen only when a concern
 - Other agencies (on-site or off-site)
 - 27% screen all children
 - 64% screen only when there is a concern
- Child care programs screen both infants and toddlers; however, programs are most likely to screen children over one year of age.
 - 76% Birth-6 months
 - 88% 6-12 months
 - 94% 12-24 months
 - 97% 24-36 months
- Child care programs reported that screenings are typically held on-site.
 - 70% On-site
 - 16% On-site and off-site
 - 14% Off-site only
- Most child care programs screen children once a year or more.
 - 62% Once a year or more
 - 11% Every 2-3 months
 - 24% Every 6 months
 - 27% Once a year
 - 3% When enter program
 - 35% Other (when there is a concern)

- Child care programs report that nurses, program directors, and teachers conduct the screenings.
 - 52% Nurses
 - 25% Program directors
 - 17% Teachers
- The average number of infants and toddlers screened in a child care program is 34.
- Screenings in child care programs are picking up children who need further evaluation.
 - 12% of children do not pass developmental screenings in child care programs

FOR PROGRAMS THAT DO THEIR OWN SCREENING

- Child care programs use a variety of information, relying most frequently on staff input, parent and staff observations of child, medical history, and use of a commercial tool. Almost half of the programs also use an agency-developed tool.
 - 100% Staff input
 - 95% Parent/caregiver observations
 - 95% Child interaction with peers/sibs
 - 70% Medical history
 - 65% Commercial screening tool
 - 53% Social/family history
 - 53% Observation parent-child interaction
 - 47% Agency screening tool
- The Denver is the most common commercial tool used in child care programs, followed by the Ages & Stages Questionnaire.
 - 18% Denver
 - 18% Denver II
 - 27% Ages & Stages Questionnaire
- The Denver (I&II) and Ages & Stages Questionnaire (ASQ) are seen by child care programs as reliable and valid; easy to administer (ASQ and Denver I), and affordable (ASQ & Denver II). Child care programs feel that evaluators are more likely to respect results of the Denver than the ASQ.
- Agency developed tools are seen by child care programs as the easiest to administer. They are also viewed as affordable, reliable and valid.
 - 88% Easy to administer
 - 55% Affordable
 - 44% Reliable and valid

- Child care programs reported that parents are typically not present for the screenings.
 - 55% Parents are not present and provide no input
 - 14% Parents are not present but provide input (questionnaire/phone)
 - 23% Parents are present, observe, and answer questions
 - 9% Parents are present and assist in screening
- Child care programs reported that follow-up is provided when a child fails the screening.
 - 86% Discuss concerns with family
 - 73% Observe
 - 64% Offer activities
 - 59% Refer for alternative screening/evaluation
 - 55% Screen again later
 - 41% Refer to Child & Family Connections (CFC—the entry point for state early intervention services)
 - 41% Consult with other professionals
- Child care programs refer most frequently to the school district for follow-up developmental evaluations.
 - 45% School district
 - 37% Child & Family Connections
 - 17% Hospital/medical provider
 - 13% Private provider
 - 16% Do not refer for evaluations
- 48% of child care programs report that they receive feedback on evaluations.
- Over half of the childcare programs have no knowledge of Child and Family Connections.
 - 55% No knowledge
 - 15% Received written information about program
 - 13% Familiar, but have no written information
- In child care programs that do their own screening, if a child passes but there are still developmental concerns, follow-up is often provided.
 - 86% Discuss results with families
 - 68% Observe the child
 - 68% Offer activities to promote development
 - 64% Screen again later
 - 36% Consult with other professionals
 - 32% Refer to Child & Family Connections
- Children in child care often receive other health screenings.
 - 48% Vision
 - 44% Hearing
 - 23% Lead
 - 52% Iron

- Child care programs are more likely to reach out to other agencies for assistance in screening, than other agencies are to contact child care programs.
 - 65% Contact other programs to request screenings
 - 39% Contacted by other programs and offered screenings

- Early Intervention programs collaborate most frequently with child care programs to provide screenings.
 - 52% Early intervention programs
 - 29% Public health programs
 - 23% Child and Family Connection sites
 - 9% School districts

- Child care programs that arrange for others to do the screenings or who refer out are more satisfied with the screenings than programs whose staff conduct the screenings. However, they also know less about the screenings (tools used, who screens, how results are shared)

Program staff screening	Other
10%	40% Very satisfied
48%	30% Satisfied
43%	30% Somewhat satisfied

- 73% of child care programs are satisfied/very satisfied with screenings provided by other agencies.
 - Dissatisfaction comes from:
 - 19% Lack of feedback (feedback probably goes directly to parents)
 - 10% Waiting lists for screening services

- Child care programs reported the following strengths of their screening procedure:
 - Helps parents understand their child's needs
 - Screening is easy to do/interpret
 - Screeners have good training and experience
 - Screening is done on site (so convenient for staff and family)

- Child care programs reported the following weaknesses of their screening procedure:
 - Staff lack experience and training
 - Screening not done in a timely manner and done infrequently
 - Limited time or space to conduct screening

- Child care programs reported their greatest unmet needs regarding developmental screening and referral to be:
 - Poor knowledge of what services/resources exist
 - Lack of parent understanding of need for developmental screening- so limited follow through
 - Lack of training regarding screening tools and providing appropriate services
 - Poor turn around time getting screening conducted or getting results

Appendix D

Unmet Needs Project

Findings at a glance: Infant Mental Health in Illinois

Infant Mental Health Survey Findings

- Survey response rates (number of surveys mailed/returned):
 - 59% (47/80) Early Intervention
 - 50% (12/24) Child and Family Connections (CFCs)
 - 46% (44/95) Public Health
 - 38% (75/195) Child Care Centers
 - 34% (91/267) Prevention Programs including:
 - 93% (25/27) Healthy Families
 - 36% (45/125) Parent Training
 - 33% (5/15) Early Head Start
 - 30% (6/20) Parents too Soon
 - 20% (1/5) Family Focus
 - 12% (9/75) Prevention Initiative
 - 41% (274/661) Total
- Surveys were mailed and data collected between January and December, 1999.
- Average number of infants and toddlers served by program:
 - Child & Family Connections: 594 (range: 207-1069)
 - Public Health Programs: 425 (range: 1-2321)
 - Prevention Programs: 182 (range: 0-5000)
 - Early Intervention Programs: 61 (range: 5-600)
 - Child Care Programs: 38 (range: 6-108)
- Across programs, total number of infants and toddlers served:
49,321 (duplicated count)
- Across programs, social/emotional concerns⁵ were identified in 16% of children:
4,914 (duplicated count)
- Percentage of infants/toddlers with social/emotional concerns varied by program:
 - 24% Early Intervention Programs
 - 16% Prevention Programs
 - 16% Public Health Programs
 - 12% Child Care Programs
 - 9% Child and Family Connections

⁵ Definition of social emotional/concerns used in the survey: Social/emotional concerns are seen in behaviors that occur in a child more often or last longer when compared to other children in the child's age group such that you or your staff are concerned. These behaviors include but are not limited to excessive hitting or biting, over-activity, under-activity, extreme fearfulness/withdrawal, inconsolable crying, excessive tantruming, self-harming behaviors (head banging/self-biting), and avoiding social interaction.

- Across programs, there was a range in the intensity of concerns identified:
 - 65% Mild concerns: Ongoing difficulties responding to regular program services
2,473 infants/toddlers
 - 28% Moderate concerns: Serious difficulties requiring additional intervention
1,158 infants/toddlers
 - 7% Severe concerns: Require urgent attention
401 infants/toddlers
- Percentages of programs that reported that they have had to ask families to withdraw their child due to social/emotional problems:
 - 42% Child care
 - 6% Early Intervention
 - 3% Prevention
 - 2% Public health
 - 0% Child and Family Connections
- Programs reported that the most frequent reason for asking a family to withdraw their child was biting (40%). Other reasons included:
 - 35% Hitting/Aggression*/Harming others*
 - 4% Over-activity
 - 4% Excessive tantruming
 - 4% Inconsolable crying
 - 4% Mental health/attachment*
 - 4% Socialization issues*
 - 2% Self-harming behaviors
 - 0% Under-activity
 - 0% Extreme fearfulness/withdrawal
 - 0% Avoids social interaction
 - *not included in survey definition
- Percentages of programs that reported family mental health concerns:
 - 69% Chemical dependency
 - 64% Troubled parent/child relationships
 - 64% Child abuse/neglect
 - 64% Domestic violence
 - 62% Depression
 - 46% Other mental health concerns
 - 11% Other (child disability, parent disability, homelessness, community violence, poverty, divorce/custody issues)
- Child Care Programs, overall, were less likely to report family concerns. Of the prevention programs, Parent Training Programs were less likely to report family concerns.
- Programs reported that family social/emotional concerns were most difficult for staff.
 - 63% Most difficult staff concerns were related to families
 - 37% Most difficult staff concerns were related to children

- Programs reported that the three most difficult family concerns for staff were:
 - Child abuse/child neglect
 - Parental mental health (depression, bipolar disorder, schizophrenia, and undiagnosed mental illness)
 - Domestic violence
- Programs reported the three most difficult child concerns for staff were:
 - Biting
 - Tantruming
 - Hitting
- Programs reported that they meet social/emotional/mental health needs in a variety of ways, primarily through referral to outside agencies for additional services and their regular staff.
 - 80% Refer to outside agencies
 - 50% Rely on regular staff
 - 32% Use staff with special training
 - 31% Use mental health consultants
- Programs differed in how likely they are to have staff with special training or consultants in mental health/social/emotional development. EI and prevention programs were most likely, and public health were much less likely, to have mental health consultants. The percentages of programs that reported consultants or staff with mental health training were:
 - 86% Early intervention programs
 - 74% Prevention programs
 - 56% *Child care programs***
 - 50% Child and Family Connections
 - 11% Public health programs
- Programs reported that their staff with special training was most likely to be a social worker:
 - 57% Social worker (29)
 - 20% Psychologist (10)
 - 8% Counselor (4)
 - 6% Child Development Specialist (3)
 - 6% Director (3)
 - 4% Nurse (2)

Other staff included family case manager, parent liaison, family support coordinator, play therapist, and special education teacher.

- Programs reported that their mental health consultants were most likely to be a social worker or psychologist:
 - 33% Social worker (16)
 - 27% Psychologist (13)
 - 19% Counselor (9)
 - 8% Nurse (4)
 - 8% Therapist (4)
 - 4% Psychiatrist (2)

- Programs reported that they use specially trained mental health staff or consultants to provide:
 - 90% Intervention
 - 51% Child/Family Assessment
 - 30% Staff Consultation

- Programs reported that specialists provide child (25%) and family (17%) assessment of social/emotional concerns.
 - Child assessment was available in:
 - 37% Prevention Programs
 - 36% Early Intervention Programs
 - 27% Child Care Programs
 - 25% Child and Family Connections
 - 4% Public Health Programs
 - Family assessment was available in:
 - 36% Early Intervention Programs
 - 30% Prevention Programs
 - 17% Child and Family Connections
 - 15% Child Care Programs
 - 9% Public Health Programs

- Programs reported that specialists provide both behavioral interventions and psychotherapy. Families were involved in the interventions (51% involve families; 39% child only).
 - 24% Child behavioral intervention in classroom
 - 24% Child behavioral intervention with family
 - 18% Parent Counseling/Psychotherapy
 - 15% Individual child therapy
 - 9% Parent/child psychotherapy

- Many programs that do not have mental health consultation reported that they would like to have such a service. The greatest demand for consultation was reported by child care and prevention programs. Programs that reported that they would like mental health consultation:
 - 69% Child Care Programs
 - 66% Prevention Programs
 - 52% Early Intervention Programs
 - 42% Child and Family Connections
 - 34% Public Health Programs

- Programs that would like consultation reported that they would like the consultant to address:
 - Adult mental health disorders
 - Child behavior concerns
 - Teenage parents
 - Violence
 - Child abuse
 - Substance abuse
 - Parent/child interactions

- 94% of programs surveyed reported making mental health referrals to a variety of providers. Referral rates to Child and Family Connections and community mental health providers differed across programs surveyed.
 - 61% of all respondents refer to Child and Family Connections.
 - 87% Public Health Programs
 - 76% Prevention Programs
 - 60% Early Intervention Programs
 - 25% Child and Family Connections
 - 37% Child Care Programs
 - 58% of all respondents refer to Community Mental Health Services.
 - 69% Public Health Programs
 - 67% Child and Family Connections
 - 64% Prevention Programs
 - 51% Early Intervention Programs
 - 47% of all respondents refer to Child Care Programs
 - 30% of all respondents refer to School Districts
 - 25% of all respondents refer to Private Providers
 - 23% of all respondents refer to Medical Centers
 - 14% of all respondents refer to other providers including EI, Special education, Local agency Networks (LANs), domestic violence center, and behavioral specialists.

- Programs surveyed reported that a range of mental health services is available in most communities.
 - 65% Parent counseling/psychotherapy
 - 64% Diagnostic evaluation
 - 64% Individual child therapy
 - 59% Mental health consultation
 - 53% Parent/child psychotherapy
 - 9% Therapeutic nursery

- However, programs surveyed reported that the amount of services in communities is clearly not adequate to meet the needs.
 - 62% No, not adequate to meet needs
 - 38% Yes, adequate to meet needs
 - 100% Child and Family Connections report that the amount of services is not adequate to meet the community needs.

- 80% of programs reported that they regard training in social/emotional/mental health as a moderate to high priority. Prevention programs were most likely to rate training as a high priority (37%). Public health programs and Child and Family Connections were least likely (18/17%)
 - 29% high priority
 - 51% moderate priority
 - 20% low priority

- Across programs, respondents reported that the following types of trainings would be most useful:
 - 72% Identifying social/emotional/mental health concerns in infants/toddlers
 - 54% Initiating discussion with families about child concerns
 - 39% Working with families around concerns about child behavior/social/emotional/mental health
 - 39% Identifying social/emotional/mental health concerns in parents

- Prevention Programs most want training in:
 - 71% Identifying concerns in infants/toddlers
 - 53% Initiating discussions with families
 - 50% Identifying concerns in parents

- Child Care Programs most want training in:
 - 84% Identifying concerns in infants/toddlers
 - 64% Initiating discussion with families
 - 52% Working with families around child concerns

- EI Programs most want training in:
 - 57% Initiating discussion with families
 - 51% Identifying concerns in infants/toddlers
 - 47% Working with families around concerns

- Public Health Programs most want training in:
Identifying concerns in infants/toddlers (80%)
Identifying concerns in parents (47%)
Making referrals for additional services (40%)
- Child and Family Connections most want training in:
Identifying concerns in infants/toddlers (67%)
Initiating discussion with families (67%)
Identifying concerns in parents (50%)
Making referrals (50%)
- Only 30% of programs reported that they feel prepared to meet the social/emotional needs of infants, toddlers, and families.
 - 5% Very prepared
 - 25% Prepared
 - 54% Somewhat prepared
 - 14% Not prepared
 - 2% Not at all prepared.
- Programs with specially trained staff or consultants reported that they are more prepared to meet social/emotional needs of infants, toddlers, and families than programs without such expertise.
- Programs surveyed were asked to report one change/addition that would better prepare them to meet social/emotional needs. Across programs, responses were:
 - More training
 - Additional staff/consultants with training in mental health
 - Expanded/adapted services to help address social/emotional issues
- Programs surveyed identified the following areas as the greatest unmet needs in their communities:
 - Availability of mental health services
 - Availability of trained therapists for infants and toddlers
 - Funding for services

Illinois Infant Mental Health Survey: Findings and Recommendations

INTRODUCTION

In November, 1999, the statewide Social and Emotional Committee formed to ensure that families with infants and toddlers in Illinois have access to services that support healthy social and emotional development. The Committee evolved from needs identified through the Birth to Three Project, the Unmet Needs Project, and Voices for Illinois Children. The Committee is co-chaired by Karen Freel, Ounce of Prevention; Ann Cutler, Unmet Needs Project, and Gaylord Gieske, Voices for Illinois Children. The Illinois Infant Mental Health Association is also a key partner of the Committee. The Committee includes a large group of stakeholders including representatives of different divisions of the Illinois Department of Human Services; providers from a range of settings including child care, Early Intervention, prevention, public health, and mental health; researchers, faculty, and advocates.

As part of the work of the statewide Social and Emotional Committee, the Unmet Needs Project, a joint effort of the University of Illinois and the Erikson Institute, conducted a survey of over 600 early childhood programs regarding the needs and services for infants, toddlers, and their families with social/emotional, mental health, or behavioral concerns. The survey included prevention programs, childcare programs, public health programs, early intervention programs (EI), and Child and Family Connections (CFC). The survey response rate was high (41%), with 274 programs serving 49,321* infants and toddlers participating. The survey used the following definition for social/emotional concerns:

Social/emotional concerns are seen in behaviors that occur in a child more often or last longer when compared to other children in the child's age group such that you or your staff is concerned. These behaviors include, but are not limited to: excessive hitting or biting, over-activity, under-activity, extreme fearfulness/withdrawal, inconsolable crying, excessive tantrums, self-harming behaviors, and avoidance of social interaction.

The major findings and recommendations are presented below.

*** This figure represents a duplicated count, as children enrolled in one program may also be seen in another service setting.**

PREVALANCE OF SOCIAL/EMOTIONAL CONCERNS

Social/emotional concerns are present in a significant number of children ages birth to three.

16% of children aged birth to three have social/emotional concerns. While the majority of these concerns are mild and respond to program services, over 1/3 of the children identified have serious difficulties that require additional, often urgently needed intervention services. Early intervention programs report the highest percentage (24%) of children with social/emotional concerns.

Infants and toddlers may be excluded from services because of social/emotional problems; further, family life may be severely impacted by behavior problems in children under three.

42% of childcare programs have had to ask a family to withdraw an infant/toddler because the program was unable handle the child's social/emotional problems.

The most challenging child behaviors in group care are biting, tantrums, and hitting. In addition to the survey, the Unmet Needs Project conducted focus groups with parents of children in EI. Parents report intense distress and family disruption from difficult child behaviors including excessive tantrums, throwing objects, hitting, inconsolable crying, and sleep problems. Because of these behaviors, parents are not able to find babysitters. Further, parents hesitate to ask family members to help, when child behavior is so difficult. Parents stop taking their child out to stores, restaurants, even church. Without effective help, parents can become exhausted, angry, and depressed. Some parents reported being so worn out that it was difficult for them to focus on their child's therapies or even to have fun with their children.

Mental health concerns are present in some families served in infant/toddler programs. Family mental health issues are the most difficult challenges that infant/toddler staff face.

Programs report that families experience chemical dependency, troubled parent/child relationships, child abuse/neglect, domestic violence, depression, and other mental health concerns (e.g., schizophrenia, obsessive-compulsive disorder). When asked about the most difficult staff challenge, 63% of programs identified parental mental health as their greatest concern.

PROGRAM/COMMUNITY CAPACITY TO MEET NEEDS

Programs meet social/emotional/mental health needs primarily through referral to outside agencies for additional services and through their regular staff. However, there are problems with each of these options. Referrals to outside agencies are complicated by the fact that mental health services in communities are not sufficient to meet the needs, nor are the staffs of community mental health services trained to work with infants, toddlers, and their families.

100% of CFCs report that the amount of mental health services is not adequate to meet community needs. 62% of all programs report the same finding. Further, programs report that mental health in communities staff do not have training in infancy and parent/infant work.

Relying on regular program staff is also problematic, as programs do not feel prepared to meet the social/emotional needs of the children and families they serve and feel their staff are not adequately trained in this area.

70% of programs report that they are not adequately prepared to meet the social/emotional needs of infants/toddlers and families. 80% of programs report staff training in this area as a high priority.

Programs are more prepared to meet social/emotional needs *if* they have specially trained staff or consultants.

The presence of specially trained staff or consultants (e.g. social workers, psychologists, counselors, child development specialists) increases the likelihood that programs rate themselves as prepared to meet social/emotional needs. EI and prevention programs are most likely to have specially trained staff; public health programs are least likely.

Many programs that do not have specially trained staff or consultants place a high value on these services and want to add these experts to their team to address pressing needs for infant and family mental health services and for staff training.

When asked what one change would better prepare the program to meet the social/emotional needs of families, programs listed more training and the availability of additional staff/consultants with expertise in infant mental health as their top requests.

Programs identified the following areas for consultation: parent/child interactions, adult mental health disorders, difficult child behavior, teenage parenting, community and domestic violence, child abuse and neglect, and substance abuse.

Staff training in social/emotional/mental health needs of infants, toddlers, and their families is a top priority.

80% of programs regard training in social/emotional/mental health needs as a priority area for training. Across groups, the most pressing needs for training are in identifying social/emotional concerns, initiating discussion with families about child concerns, working with families around the child's needs, and identifying social/emotional/mental health concerns in families.

UNMET NEEDS IN ILLINOIS

To better prepare programs to meet social/emotional needs, programs want:

- More training
- Additional staff/consultants with training in infant mental health
- Expanded/adapted service models

The greatest unmet needs in communities related to social/emotional of infants and toddlers are:

- Lack of mental health services appropriate for the needs of very young children and their families
- Lack of trained therapists/specialists in infant mental health
- Lack of funding for services

RECOMMENDATIONS

By building upon the existing service systems and the work of the statewide Social and Emotional Committee, there are many steps that can be taken to address the unmet social/emotional needs of infants, toddlers, and their families in Illinois.

Identifying children with social/emotional/mental health concerns

There is an urgent need to identify appropriate screening tools and assessment procedures for social/emotional concerns in children ages birth to three and to train providers of developmental screening, diagnostic, assessment, and intervention services in these measures. The Special Advisory Panel for Early Intervention has appointed a subcommittee on social/emotional development to examine issues related to Part C services. The sub-committee has identified appropriate screening and assessment tools for social/emotional development in birth to three population and is developing recommendations for a statewide training-the-trainer approach to disseminate this knowledge within the EI system. The information on social/emotional screening and assessment gathered for Part C services can provide much needed resources and directions for other infant/toddler settings.

Communicating and working with parents regarding these concerns

Staff best learn how to work with families and children with complex issues through ongoing supervision and consultation directly related to the families they serve. Thus, policies should be developed to provide that mental health consultation be a component of state-supported infant/toddler programs including childcare, prevention, early intervention, and public health. Early Head Start already has this requirement and has a national task force working to develop a model for such services. Mental health consultation has been identified as a key priority for the statewide Social and Emotional Committee. The Committee has identified several communities in Illinois who have initiated mental health consultation and is working toward defining recommended practices for infant mental health consultation. National models suggest that the cost for consultation is not excessive, and that consultation is an effective means for staff development and quality improvement.

Integrating Infant Mental Health Services into Existing Service Systems

There is an urgent need to increase the availability of infant mental health treatment services including parent/infant psychotherapy, parent counseling, and specialized child therapies in communities. The EI system provides the infrastructure to begin to address this need, in part through the recent addition of Relationship and Attachment Disorders to EI eligibility. The EI Social/Emotional Task Force is preparing recommendations related to the diagnosis, assessment, and intervention for Relationship and Attachment Disorders. Further, they are reviewing other social/emotional/mental conditions impacting on child development that might also be addressed through EI. Experts in Illinois as well as other states have designed models for group therapy in childcare centers for children with social/emotional/mental health concerns. Early Head Start programs, including the Ounce of Prevention program in Chicago are developing models of service that provide mental health treatment services on-site. These models could provide examples of integrated service provision and blended funding. The

statewide Social and Emotional Committee, the Unmet Needs Project and the sub-committee of the Special Advisory Panel for Early Intervention stand ready to assist in developing recommendations for an integrated service system.

Coordination of Infant Services with Adult Mental Health Treatment

Clearly, an effort is needed to link the world of infancy with the world of adult mental health services. Laying the foundation for emotional and social competence in young children is a key to healthy development lifelong. Further, children's early development depends upon the health and well-being of their parents and the adults who care for them. As noted in the National Academy of Sciences report, *Neurons to Neighborhoods*, a significant number of young children are burdened by the untreated mental health problems in their families. Providing parents with accessible, meaningful mental health services is crucial to their own functioning *and* that of their children. As noted infant programs serve families with mental health problems; understanding how to work with these families and how to facilitate effective mental health referrals is a high priority staff need. Mental health professionals treat adults who are parents of children ages birth to three, often without focusing on parenting issues as many lack knowledge of infant development or exposure to clinical approaches to parent/infant work. The linkage between these two professional communities is essential for the well-being of children and their families. This linkage will involve awareness education, coordination of services, professional development and training, and integrated funding streams—all possible given a shared commitment to infant and adult mental health.

Personnel Standards and Professional Education

Diagnosis, assessment, and intervention with social/emotional mental health disorders of infancy requires focused training in child development, family dynamics, parent/child relationships, developmental psychopathology, and treatment/intervention approaches. As noted, the EI sub-committee is developing recommendations for personnel qualified to identify and intervene with Relationship and Attachment disorders within the EI system. The Illinois Association of Infant Mental Health is considering developing standards for an Infant Mental Health credential that could apply across service systems. All of these efforts will be coordinated with the Illinois Interagency Council on Early Intervention and the statewide Social and Emotional Committee of the Birth to Three Project. The collaborative development of personnel standards and certificate requirements will drive the initiation of infant mental health training in colleges, universities, and other training institutions. Over 60 social workers, psychologists, and developmentalists participated in a recent advanced training seminar in mental health consultation to infant/toddler programs. Many of these persons are providing consultation already to infant/toddler centers. While clearly many more trained professionals are needed, the nucleus of an infant mental health workforce has begun to form.

CONCLUSION

The social/emotional well-being of children and families is increasingly cited as a key to healthy development in general, and as foundation for all learning, including success in school. Children vary in their risk for behavioral and emotional difficulties. While children in high-risk communities tend to be at greater risk, social/emotional mental health concerns in children occur across groups and in all communities. Fortunately, there are many recent advances in the identification and intervention with children's mental, social, and behavioral health, including help for children ages birth to three. Building upon the strong foundation of infant/toddler services in Illinois, we can move toward the creation of a system of mental health services for our youngest children and their families. The statewide Social and Emotional Committee is committed to working with all stakeholders to make this a reality for the children and families of Illinois.