

South Carolina  
Self-Assessment Part C  
Public-Input Report

June 2001

prepared for

**Babynet**  
South Carolina's  
Early Intervention Program

by

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# Chapter One

## Introduction

The Program for Infants and Toddlers with Disabilities (Part C of IDEA) is a federal grant program that assists states in operating a comprehensive statewide program of early intervention services for infants and toddlers with disabilities (birth to three years) and their families.

Congress established this program in 1986 in recognition of "an urgent and substantial need" to

- enhance the development of infants and toddlers with disabilities;
- reduce educational costs by minimizing the need for special education through early intervention;
- minimize the likelihood of institutionalization and maximize independent living; and
- enhance the capacity of families to meet their child's needs.
- (and added in the 1997 reauthorization) enhance the capacity of states and local programs to meet the needs of underrepresented populations, particularly minority, low income, inner city, and rural populations.

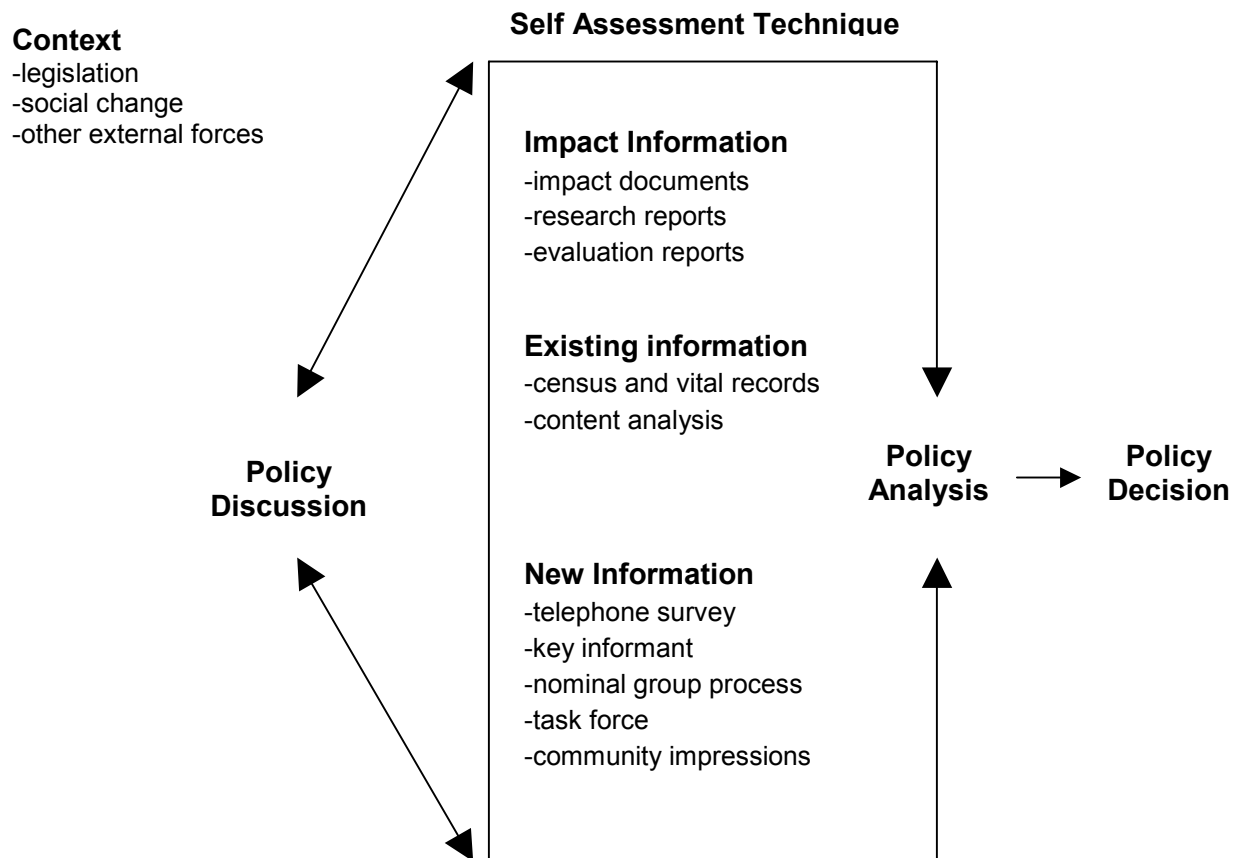
In April 2000, South Carolina was notified of its selection for federal monitoring of its Part C early intervention and Part B special education programs by the United States Department of Education, Office of Special Education Programs (OSEP). In response to this notification, South Carolina established two steering committees, (one for Part C and one for Part B), to facilitate the work of the self-assessment. The Institute for Families in Society at the University of South Carolina was contracted to direct the public input efforts for Part C.

Public Input took the form of focus groups, key informant interviews, and a telephone survey of current users and graduates of the Part C program. The input was concentrated in five cluster areas: Early Intervention Services in Natural Environments, Family-Centered Services, Comprehensive Child Find and Public Awareness, Early Childhood Transition, and General Supervision. The results are reported using the data generated for each of these five clusters.

## Data Collection Methods

A mixed methods approach was employed using key informants, focus groups, and a telephone survey to solicit public input on the Part C early intervention program. This program will be referred to as the BabyNet Program throughout this report. The quality of information about an issue is only as good as the technique or combination of techniques used to gather data. A single technique may be too narrow in the information it provides; using too many methods may be costly in terms of time and dollars. Different information gathering techniques are appropriate for different needs. Therefore, the following framework was used to guide the work.

**Figure 1**



### ***Focus Groups***

Focus groups use a discussion format, guided by a facilitator, to gather information on a given topic. Focus groups provide an understanding of the range and depth of opinions/feelings/beliefs, rather than the number of people who hold a particular view or opinion. Focus groups are a qualitative research technique best used when the aim is to explore an issue, and may be used prior to quantitative data collection.

Participants for the focus groups were selected whenever possible via stratified random sampling to get representation from different provider groups (i.e., primary care physicians, therapist, early interventionists, BabyNet coordinators, family advocates, and Title V program coordinators) and parents representing rural or under represented segments of the population within the BabyNet Program. To avoid overlap with other methods, parents who participated in the focus groups were excluded from the sample drawn of parents selected to complete the survey. To ensure that there would be between 6 and 10 members per group - the recommended number for a successful focus group discussion - the decision was made to over-sample and to double the numbers of focus groups with parents. A total of 75 providers and 20 parents participated in focus groups. (See Appendix A - Focus Groups and Key Informants.)

Focus group data were collected on large newsprint paper -this allows all participants to monitor what is being recorded and identify with the discussion. Notes were taken throughout the entire focus group. As soon as possible after the focus group broad impressions were written down documenting feelings about how the group process worked and any limitations or procedural variations that became evident throughout the process. The focus group data were examined by means of theme analysis, which involves analyzing and organizing the themes or patterns indicated by the data. The notes were coded independently by three members of the research team and according to the five cluster areas. The coding was reviewed and verified with the findings reported in this report. Focus groups did not exceed two and a half hours in length. A gift certificate of ten dollars was provided to every caregiver who participated in the focus group. *The reader is cautioned that it is completely inappropriate to attempt to quantify focus group data using statistical methods. Therefore, the focus group findings are reported throughout the document, integrating the findings of the various methods.*

### ***Key Informant Interviews***

The key informant method is based on obtaining information, over time, from key stakeholders who are in a position to know both the community and the BabyNet Program well. The person or persons selected to be key informants must therefore have a broad knowledge of the community, its services, and its people. For purposes of this study, public officials, longtime steering committee members, and administrators were selected to participate as key informants. The key informant method requires sufficient time to build a good relationship between investigator and informant. The value of the method is the type of data that can be elicited because of the communication and trust that develops between the two. The quality of information obtained is dependent on the ability of the investigator to draw out the key informant's capabilities in perceiving and communicating the information needed. The data were examined by means of theme analysis, which involves analyzing and organizing the themes or patterns indicated by the data. The notes were coded independently by three members of the research team and according to the five cluster areas. The results are reported throughout the document integrating the findings of the various methods. Twelve key informant interviews were completed for this study averaging forty minutes in length.

### ***Caregiver Survey***

The survey technique is unique in that it is the only assessment method - other than talking to every citizen - that has the potential of representing all people in the community. In this respect, it is a relatively inexpensive way to gather information from a large number of people. If a survey is well designed and implemented, the results can be generalized to a larger population. The survey designed to elicit public input used a stratified random sample of current and former parents of BabyNet Program participants. The survey asked each participant via a telephone interview to supply attitudes, beliefs, behaviors, and attributes in response to specific questions regarding their experiences in the BabyNet Program.

The survey design incorporated flexibility in the types of questions asked, from structured yes-no-undecided responses to unstructured, open-ended responses. This format allowed for sensitivity to psychological obstacles that might affect responses, such as length of survey, wording, type of person administering it, and confidentiality. The survey data were analyzed

using the Statistical packet for the Social Sciences. Open-ended questions were coded before conducting an analysis of the major themes of the responses. Four hundred and thirty-nine telephone survey interviews were completed. All interviews were completed by the child's caregiver. The results are reported in the next section of this report.

### ***Limitations of the Study Approach***

As with any self-assessment, this study has some limitations that must be taken into consideration when reviewing and applying the findings. The focus group and key informant methodologies rely heavily on the individuals' understanding of issues and their willingness to self-disclose. Disadvantages to these methods include the following:

- Difficulty in detecting possible bias by the group facilitator was minimized by using two different formats for capturing the information (i.e., easel paper and audio recording). Inter-rater reliability procedures were developed to limit potential bias in data analysis.
- Analysis categories may not accurately represent important ideas requiring that earlier information be carefully examined before excluding from the key findings-
- The possibility of recording irrelevant information or of omitting relevant information requires the ability to scan all the information.
- Time required to select the best informants and to build trust with key
- stakeholders might result in extending the time to complete the interviews
- Personal relationship between researcher and informants may influence type of data obtained and bias the findings. To avoid this potential pitfall, the Principal Investigator of the project did not directly facilitate the focus groups or conduct the key informant interviews. Project staff with no direct knowledge of the participants was primarily responsible for data collection.
- Data may be difficult to quantify unless well organized immediately after each telephone interview and focus group. As described in the previous section, care was taken to ensure that a summary of the key issues was developed within forty-eight hours of the activity.

Conversely, the survey method requires rigor to assure statistical meaning. Random samples must be carefully selected.



- Results may not be valid if the survey is not designed correctly. In order to ensure content validity, the survey instrument was reviewed by an advisory committee and field-tested with parents of children with special health care needs.
- Time and expertise are required to develop the survey, train interviewers, conduct interviews, and analyze results. Therefore, the staff of the USC Survey Research laboratory was hired to conduct the telephone interview using a computer-assisted telephone survey software package allowing for callbacks in a systematic fashion.
- Survey methods have a tendency to limit the scope of data, (i.e., omission of underlying reasons and actual behavioral patterns). A combination of open-ended and structured questions was incorporated into the design in order to address the limitations of the survey format.

Every effort was made to ensure a diverse representation of interests and the accuracy of the data.

## Chapter Two

### Results and Conclusion

#### *Profiles of Participants*

Five hundred and forty-six stakeholders provided input on South Carolina's Part C program forming the basis for the public input portion of the self -assessment report. Table 1 provides a breakdown of the stakeholders by the methodology employed to gather the information.

**Table 1**  
**Public Input Participant (n = 546)**

<b>INFORMATION GATHERING METHOD</b>	<b>PUBLIC INPUT STAKEHOLDERS</b>
Focus Groups	75 representing provider groups 20 caregivers
Key Informants	12 interviews
Surveys	235 caregivers of current participants 204 caregivers of graduate participants
<b>TOTAL</b>	<b>546 stakeholders</b>

On average, providers and key informants reported working with the BabyNet early intervention program an average of five years. Caregivers indicated participating in the program an average of six months prior to the focus group meeting. Those caregivers who participated in the focus groups represented rural regions of the state, military families, or racial/ ethnic groups (i.e., African Americans and Native Americans) traditionally at-risk for poor developmental outcomes due to social and economic inequalities.

Caregivers who completed the surveys were selected using a stratified random sample of current and former program participants. The data set from which the sample was drawn was provided by the program staff on a disk using a Microsoft DOS format. One out of every three entries on the database provided to the research team was incomplete or contained outdated information. Specifically, the sample proved difficult to draw on a timely basis due to incomplete or outdated information on the reasons for program eligibility, date of birth of the child, and contact information. Table 2 provides a profile of the caregivers responding to the telephone survey.

**Table 2**  
**Characteristics of Program Participants (n = 439)**

CHARACTERISTICS	TOTAL (n=439)	CURRENT (n=235)	GRADUATE (n=204)
<b>Gender</b>			
Male	65.8% (289)	61% (144)	71% (145)
Female	34.2% (150)	39% (91)	29% (59)
<b>Race</b>			
White	56.5% (248)	57% (135)	56% (248)
Black	37.4% (164)	36% (85)	39% (79)
Multiracial	4.3% (19)	4% (10)	4% (9)
Asian	.9% (4)	.9% (2)	1% (2)
Native American	.2% (1)	NA	.5% (1)
Hispanic	.5% (2)	.9% (2)	NA
Other	.2% (1)	.4% (1)	NA

Demographic information provided by the respondents indicated the following:

- The highest level of education completed by the survey respondents: Less than High School (10.5% or 46), High School (29% or 127), Some college or Associate Degree (31% or 136), College (20.3% or 89), Post-Graduate (8.9% or 39), Refused (.2% or 1). The data indicates an educational level higher than the state average of 12 years or less for participants in the program.
- Fifty-five percent of the respondents reported annual incomes of less than \$40,000.
- The majority of respondents were mothers. Approximately eighty-four percent of the respondents were the child's mother. Approximately fifty percent of the caregivers reported working either part-time or full-time. Twelve percent of the respondents were unemployed (or 51) due to their child's disability or their own.
- Sixty-four percent (or 279) of the respondents were married and living in an urban or suburban neighborhood.

- The state of South Carolina was divided into three major regions, i.e., upstate, midlands, and low country. Thirty-five percent (or 154) reported residing in the Upstate part of the state with 33.7% (or 148) in the Midlands followed by 31.2% ( or 137) in the Low Country .
- Nineteen percent (or 83) reported having more than one child with special health care needs.

***Child Find and Public Awareness***

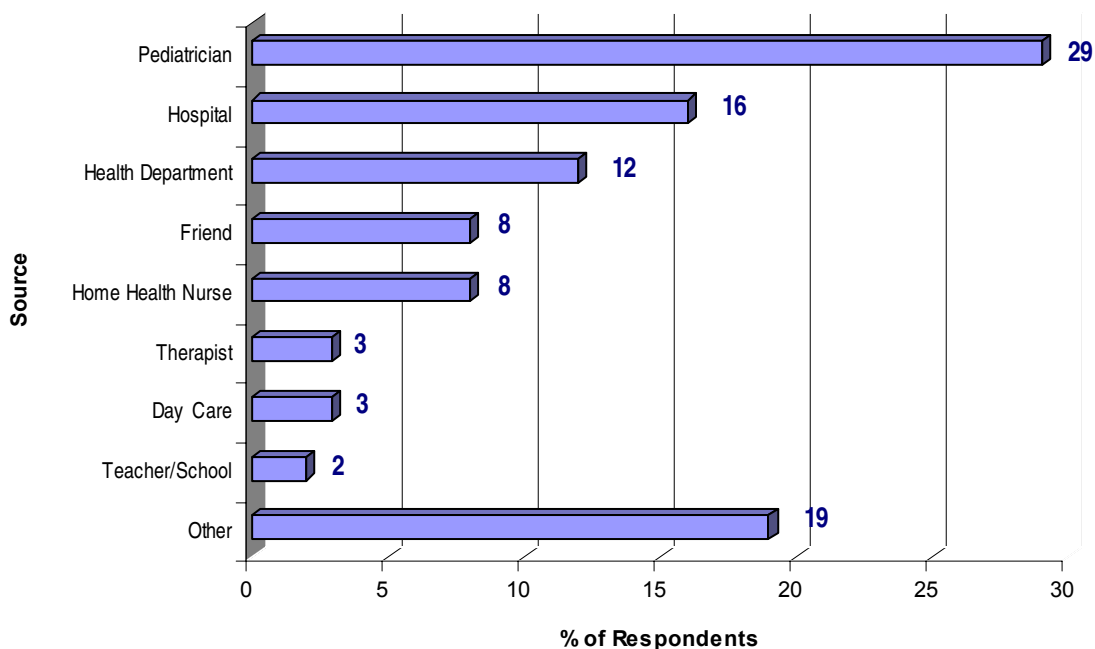
The Early Intervention Program for Infants and Toddlers with Disabilities, Part C, of IDEA requires public awareness and comprehensive child find components for children from birth through 2 years of age. These efforts must be coordinated with all other major state child find efforts.

Program participants indicated pediatricians and hospitals as the two most frequent sources of information about the BabyNet Program. However, for families graduating from the program, the Health department was listed as the source most commonly associated with information about BabyNet. Figure 2 illustrates the ways that respondents learned about the BabyNet Program.

**Figure 2 - Child Find Activities**

**"How did you learn about BabyNet?"**

**n = 439**



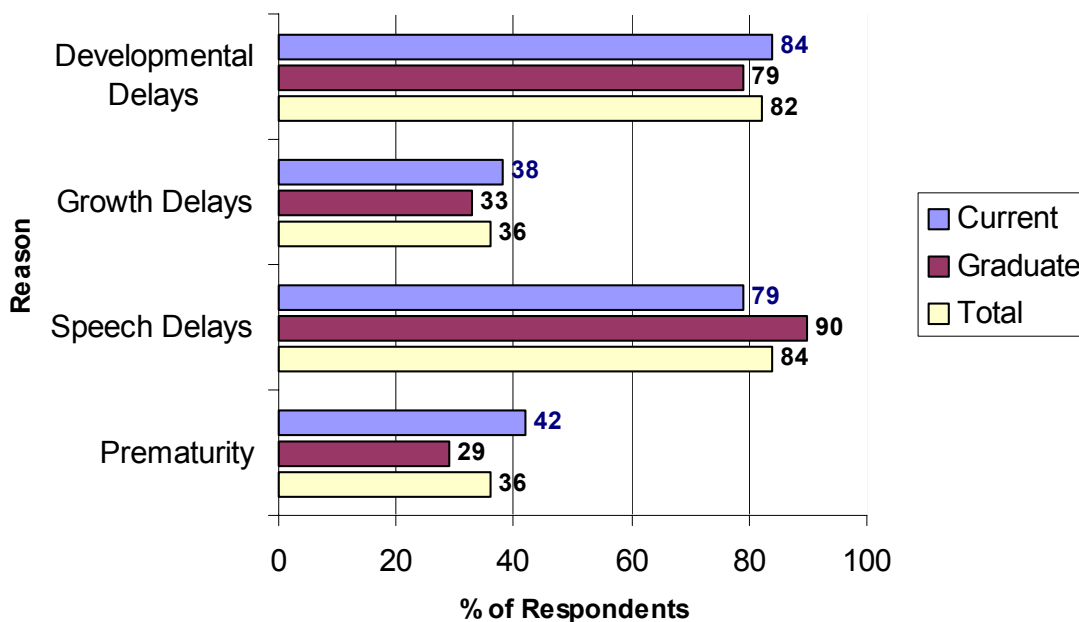
Focus group participants cited referrals through formal agencies as the best source of information on the BabyNet Program. As one program participant described their experience:

*At my child's twelve-month check-up, my pediatrician told us that my child was not developing normally ... he was not growing, moving, or doing the things like other children his age. I did not know until that day that anything was wrong with my child. Within days, the BabyNet Coordinator called me on the phone and told me about the program.*

The reason most frequently cited for entry into the BabyNet program was a medical finding of developmental delays. This diagnosis is consistent with the purpose of the program. Figure 3 demonstrates the reasons provided for program eligibility.

**Figure 3 - Program Eligibility**

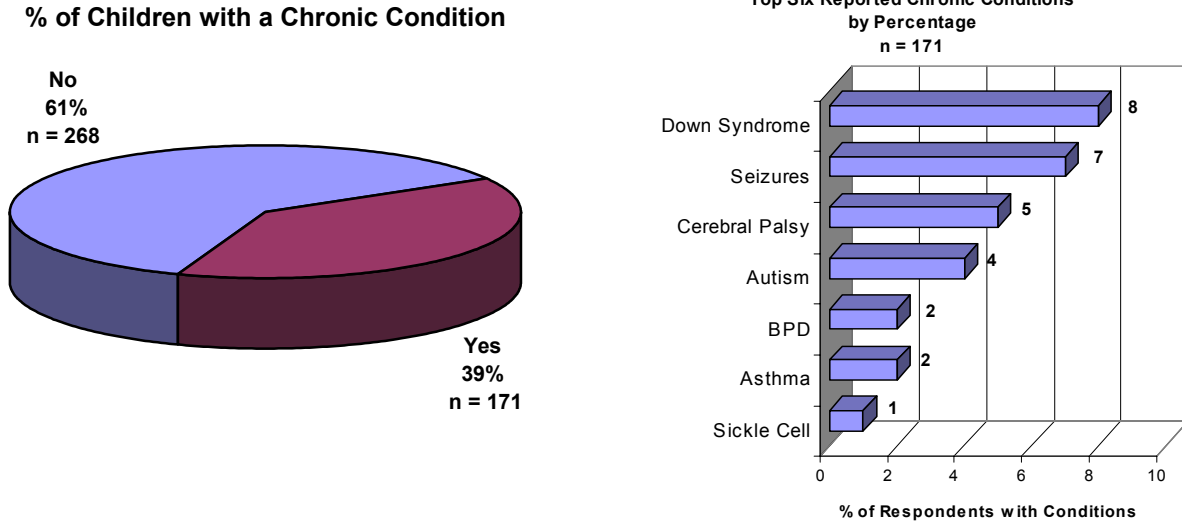
**“What reason(s) were you given that made your child eligible for the program?”**  
**n = 439**



In addition to developmental delays, many of the children reported having been diagnosed with chronic conditions resulting or leading to developmental lags. Figure 4 depicts this pattern.

## Figure 4 - Chronic Condition

"Does your child have a chronic medical condition?"  
n = 439



Caregivers with children diagnosed with chronic conditions indicated a higher referral rate through hospital or home health services than any other child activity. Current program participants reported higher rates of chronic conditions. None of the program participants specified learning about the program through brochures, radio advertisements, or health fairs. Child Find activities tended to be based on face-to-face contact with providers of services or word of mouth through a current or former program participant. Program participants gave the following examples:

*My child has Down Syndrome making her automatically eligible for this program. After her birth, I received a great deal of information from the hospital and my physician about services, people to contact, and ways to gain support for my family.*

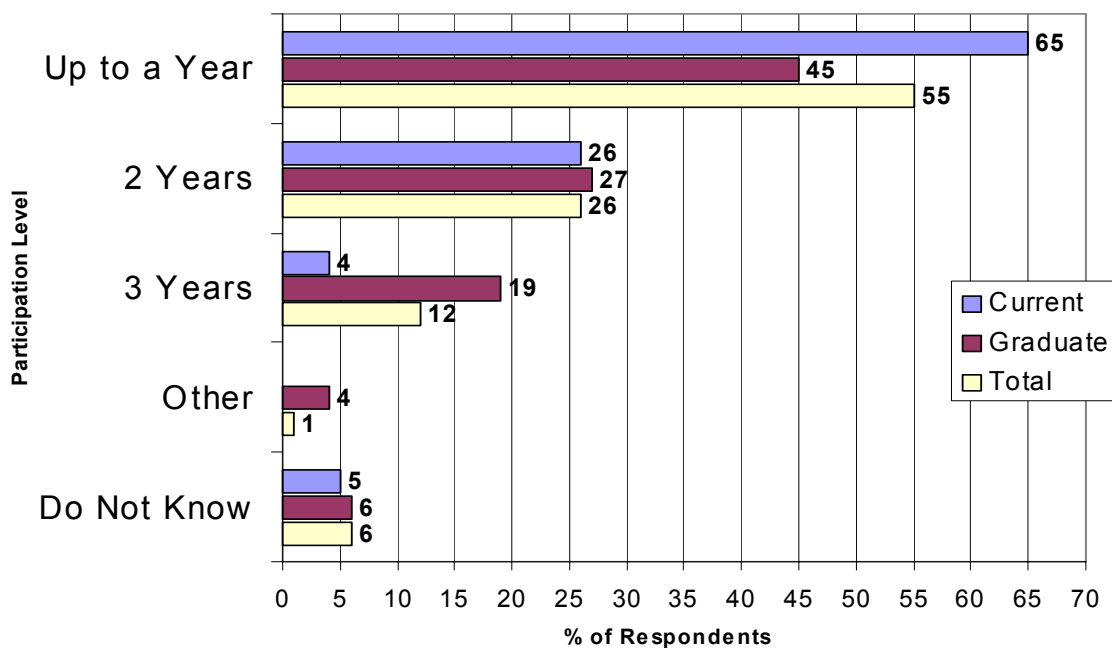
*My baby was premature and in the hospital for five months. Everyone thought my child was "brain dead" and would never do anything. BabyNet was the program that could help me get the therapies he needs to stimulate his body and mind.*

Program participants receiving referrals through the hospital, home health services, and the health department tended to enter the program within six months of their birth. In contrast, participants receiving referrals through other sources tended to enter the program after their first birthday or later. The result of this pattern is that those children enter the program later receiving early intervention services for less than the authorized number of years under the Part C program.

The late referral patterns may be due to several factors: a) providers' belief that the child does not adequately present with developmental delays, b) lack of efficacy of extensive therapeutic services prior to the age of one, and c) health care coverage limitations on assessments. Figure 5 portrays the length of time in the program reported by survey respondents.

**Figure 5 - Level of Program Participation**

**"How long (has) did your child participate(d) in the program?"**  
**n = 439**



A service provider gave the following example to illustrate the concerns with referrals to the BabyNet Program:

*As physicians, we must make responsible referrals that do not unnecessarily alarm the family. This may require that we proceed*

*with caution and observe the child. This is especially true when the medical findings do not support developmental lags. There are many therapy interventions that may not produce the end-results parents expect for their child. Once they enter this program, it is almost impossible to deny therapeutic service ...it is no longer the physician who determines medical need. The BabyNet program errs on the side of the therapist without assurance that the intervention will truly lead to better outcomes for the child ... in some cases, medical support would be of greater use to the child.*

### ***Early Intervention Services/Special Instruction***

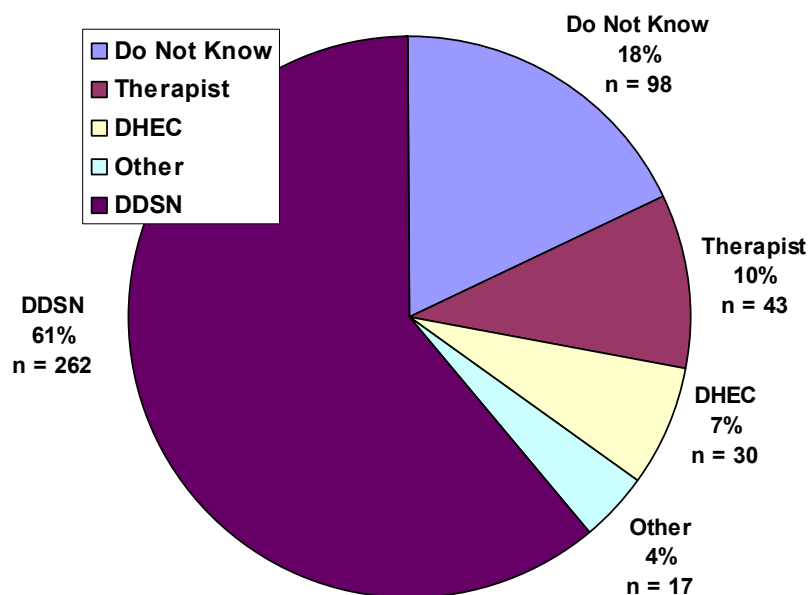
Early intervention services apply to children of school age or younger who are discovered to have developed or be at risk of developing a handicapping condition or other special need that may affect their development. Early intervention consists in the provision of services for such children and their families that have a need to lessen the effects of the condition. Early intervention can be remedial or preventive in nature - remediating existing developmental problems or preventing their occurrence (U .S. Department of Education, 1996).

Early intervention may focus on the child alone or on the child and the family together. Early intervention services may be center-based, home-based (or natural environment), hospital-based, or a combination. Services range from family training to direct therapeutic intervention. Of the 439 survey respondents, ninety-eight percent reported receiving early intervention services. However, when asked to name their early interventionist, fourteen percent (or 60) reported therapist, medical personnel or family partner as the person they view as their early interventionist. Of greater significance, eighteen percent (or 78) of the respondents did not know who provided their early intervention services. They reported receiving early intervention services from three distinct individuals citing turnover of staff as the chief reason for the number of individuals. Figure 6 displays the providers identified by survey respondents providing early intervention services for their child.



**Figure 6 - Early Intervention**

**"Who provides the early intervention services for your child?"**  
n = 430



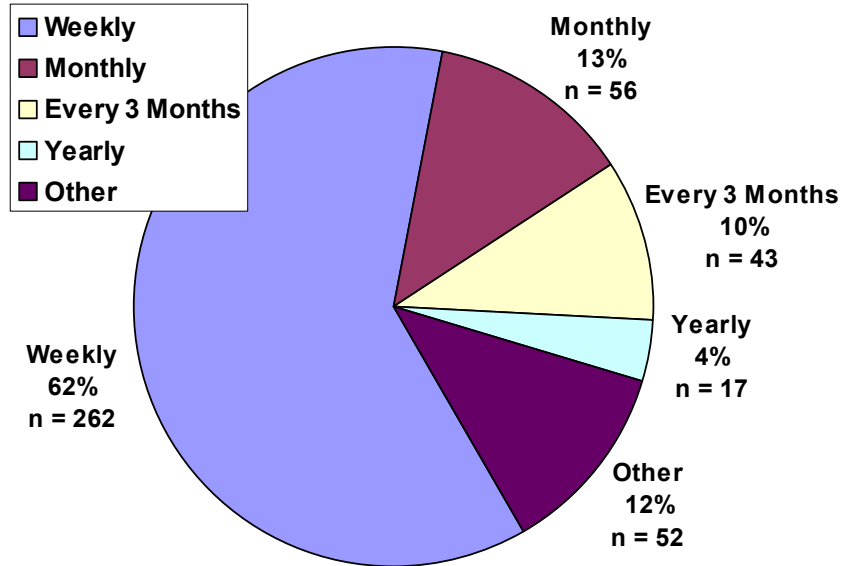
Frequency of visits provided through an early interventionist is often a function of the need of the child, length of time in the program, the number of services being provided to the child and family, and the provider environment. As indicated by a participant in the focus groups:

*There is so much to know about your child's needs ... no single visit or person can meet all the needs. The need should determine the number of visits. Paperwork should not take time away from the child and family.*

Figure 7 shows the frequency of home visits made by early interventionists to program participants. Sixty-two percent (or 262) of the survey respondents received weekly home visits by their early interventionist. Participants receiving early intervention services through the Department of Disabilities and Special Needs were most likely to receive weekly visits. In contrast, those identifying medical personnel or therapists as their early intervention provider were not as likely to receive weekly visits.

### Figure 7 - Frequency of Seeing Early Interventionist

"How often do you see (did you see) your Early Interventionist?"  
n = 430



Note: 98% or 430 of the respondents reported receiving Early Intervention services.

The provision of effective early intervention services requires that families receive needed information on available services in a manner that is culturally sensitive and easily understood by program participants. Focus groups with providers emphasized the need to expand the training of early interventionists to include a working knowledge of the health care and educational systems. Additionally, participants urged the establishment of minimum standards of competence that must be met prior to any early interventionist being assigned to a family. Central to this recommendation was the belief of the providers that "families are asking for training, not to train the early interventionist on the needs of the child." As several participants commented:

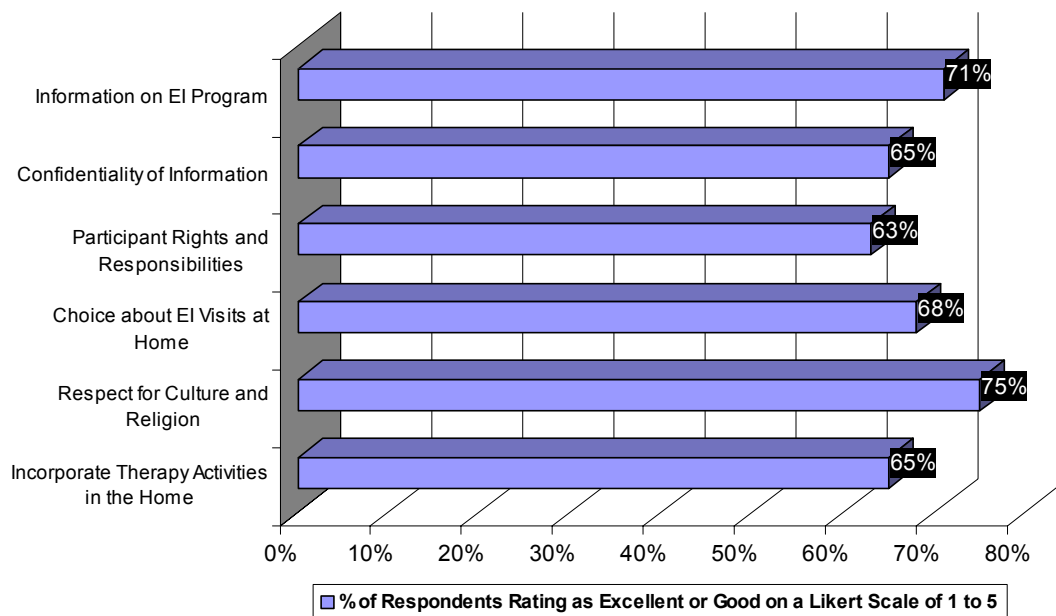
*It is not until families leave the program that many realize everything they should have been receiving through early intervention services. I never knew that there was someone who would listen to me about the Early Interventionist who came to my home - my choice was to stop the service.*

*My child was the loser in the process. The Early Interventionist who came to my home did not know anything about my child's condition or, for that matter, had never seen a child with that type of disability. They worked on paperwork each time. I needed someone to help me stimulate my child with some play therapy.*

The next figure documents the ratings of survey respondents regarding services and information provided by their early interventionist. The reader is cautioned that these ratings may be higher or lower due to the number of early interventionists providing services throughout their program enrollment.

### Figure 8 - Early Intervention Services

**"How would you rate the services and information provided to you by your Early Interventionist?"**  
**n = 430**



The data document the need to improve services and information that address several key areas: confidentiality of information provided to early interventionist, the rights and responsibilities of program participants, and the incorporation of therapeutic activities in the home to aid the development of the child. On the other hand, many participants did not recommend changes to

the role of early interventionist, instead crediting their involvement with providing the resources for their child:

*My early interventionist goes beyond what is required of her job. She often goes to the library to find out more about my child's condition or to pick up materials that might be useful in caring for my child. When I could not borrow some tapes from the university library, she arranged for me to get them and viewed them with our family. She was always two steps ahead, anticipating the best way to work with my child and the resources he needs.*

An important component of early intervention is the provision of services in the natural environment of the child, (i.e., in the home). The perceived lack of choice regarding where the services are delivered is an issue of great concern for both providers and caregivers. As several focus participants commented:

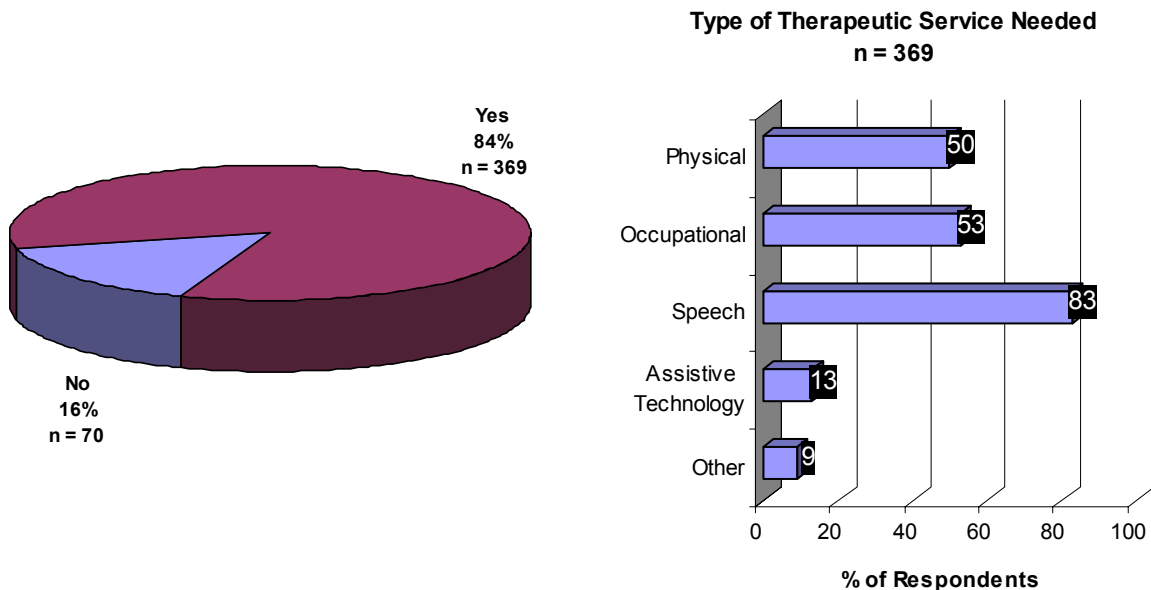
*The natural environment is not always the best way to get therapy services. It should be the parent's choice. I do not understand why the BabyNet Program does not want to cover center-based services. On the other hand, if I had four kids and limited transportation, services in my home would be great. The environment should meet the needs of the child and family and not be predetermined by the program.*

*For many children, providing therapeutic services in their home is the best way to meet their needs. However, this is a rural state with services concentrated in urban settings. Is it not a waste of time and resources to have me see three children a day versus seven? There are interventions that cannot be easily done in the home. Does this mean that the child should be restricted to equipment and activities that can only be transported or*

*supported by a home environment? If so, this is not in the best interest of children or their families.*

The implementation of services in the child's natural environment is a developing construct in South Carolina requiring careful and thoughtful planning to implement successfully in the Part C program. Figure 9 illustrates the percentage of program participants indicating a need for therapy services.

**Figure 9 - Therapeutic Services**  
**“Did your child need therapeutic services?”**  
**n = 439**



Eighty-four percent (or 369) of the survey respondents point out the need for therapy-related services. This finding is consistent with the goals of the Part C program at the federal and state levels. Overwhelmingly, survey respondents and focus participants cite therapy services as the lodestone service in the early intervention program. Yet, they express frustration at the lack of consistency in service provision due to limited statewide resources, poor reimbursement rate, and the unavailability of pediatric service providers. There are key barriers to meeting the needs of eligible children birth to three.

*A need exists to extend the eligibility of therapy services through the age of five. Many school districts are not equipped to provide*

*the services needed by young children leaving the BabyNet program.*

*BabyNet meets the current therapy needs for my child. How does it change? It changes every time we move and must rely on a different set of therapists to carry out the IFSP.*

*Therapists are not care coordinators or case managers, yet the expectation is that we provide these types of services without reimbursement. It is virtually impossible to attend meetings, answer telephone calls from Early Interventionists, physicians, or coordinators, develop home-based applications, and meet the therapeutic needs of the child.*

Caregivers express the need to have in place a system of care that is responsive to their multiple needs for information and direct services. As a group, speech therapists were reported to be better able at meeting the various needs of families enrolled in the program. A plausible explanation is the frequency and familiarity with speech therapy services experienced by the respondents. Eighty-three percent (or 306 of 362) of respondents received speech therapy through the program. A small portion of this population reported receiving only speech therapy through the BabyNet Program.

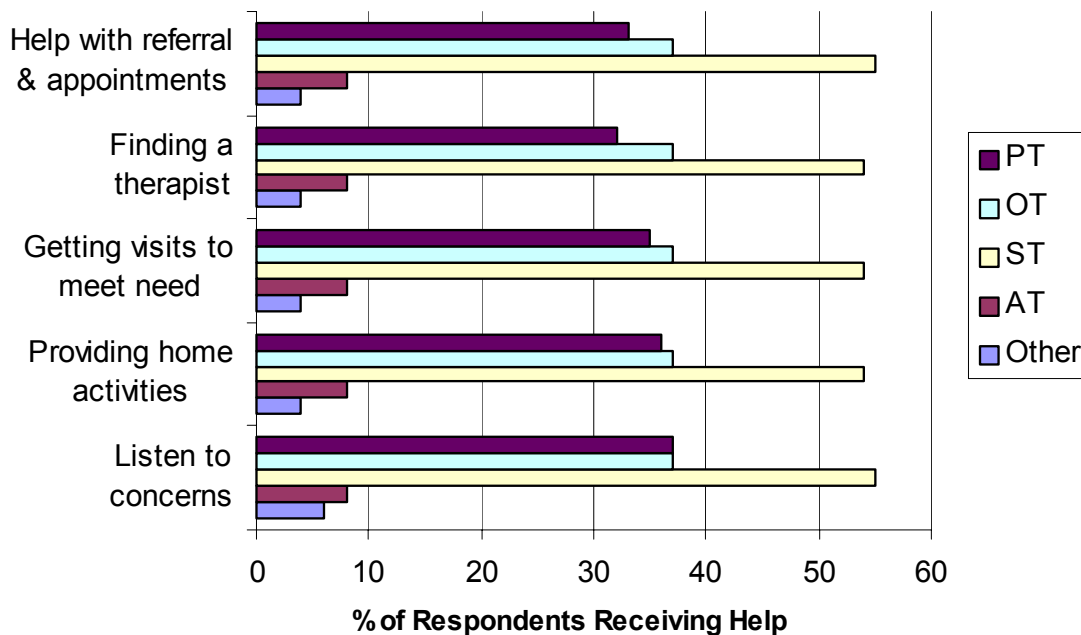
The severity of the child's medical condition and the county of residence affect the level of satisfaction with therapy services. Program participants requiring multiple therapy services express greater dissatisfaction with access to therapists and the lack of coordination of needed services than participants requiring one service. Additionally, foster care caregivers expressed the need to provide accurate information to ensure the needs of the child under their care. Yet, they cited that they often did not have the caseworkers from this agency participate in therapy sessions or in the development of the child's plan. This was described as creating a "no win" situation for the foster care child and the therapist. As one participant stated:

*I want to meet the needs of this child. They need so much and I have so little information about their background to be of any real help - this makes it harder to care for a special needs child.*

Figure 10 demonstrates the breakdown of participants needing and receiving help from their therapy provider.

**Figure 10 - Therapeutic Services**

**“Did you receive help or information with the following from your therapist?”**  
**n = 369**



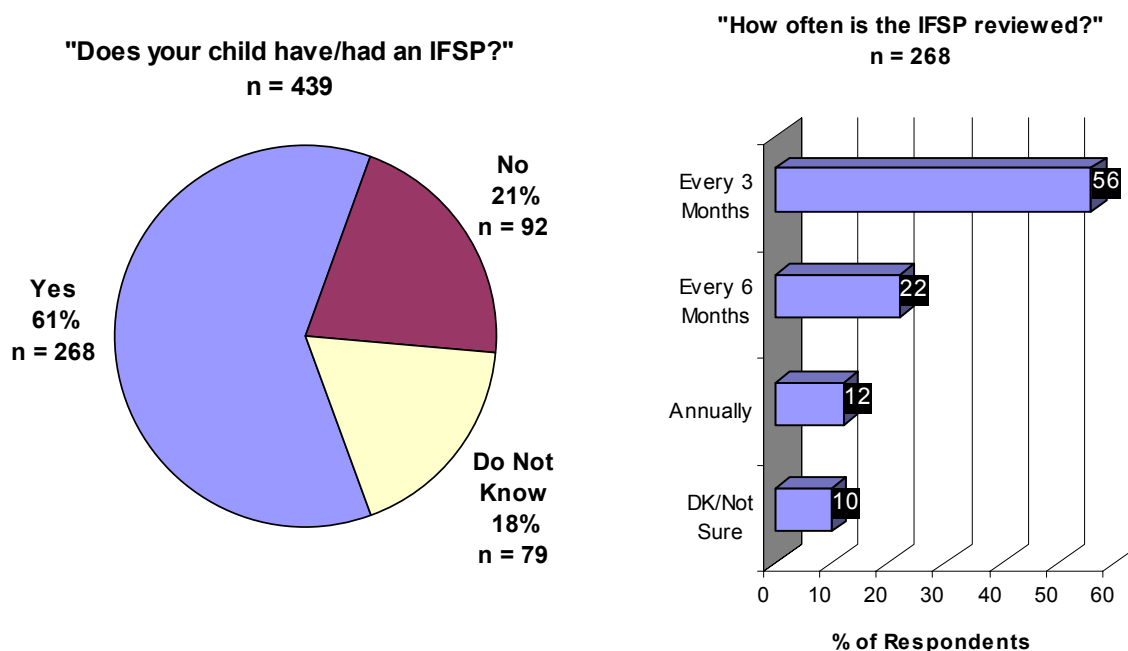
***Family-Centered Services***

Family-centered care is an approach to early intervention that offers a new way of thinking about the relationships between families and health care providers. It recognizes the vital role that families play in ensuring the health and well being of infants, children, adolescents, and family members of all ages. Family-centered practitioners assume that families bring important strengths to their experiences, even those who are living in difficult circumstances.

A family-centered approach to care empowers individuals and families and fosters independence; supports family care giving and decision making; respects patient and family choices and their values, beliefs, and cultural backgrounds; builds on individual and family

strengths; and involves patients and families in planning, delivery, and evaluation of early intervention services. Information sharing and collaboration between patients, families, and health care staff are cornerstones of family-centered care. The first step in this process is the development of an Individualized Family Service Plan (IFSP). Figure 11 illustrates the number of program participants indicating that their child has a completed IFSP.

**Figure 11 - Care Coordination Individualized Family Plan**



Approximately thirty-nine percent (or 171) of the respondents did not have or did not know if they had a completed IFSP. This finding is alarming given that the stratified random sample for survey respondents required program enrollment for a period of at least six months. This criterion was applied to the sample drawn to eliminate program participants recently enrolled in the program with insufficient time to complete the IFSP.

Of the two hundred and sixty-two respondents indicating that their child had a completed IFSP, eighty-three percent (or 220) received a copy of the plan. Ninety-five percent of the respondents (or 249) reported being involved in the design of the plan. However, of those who had a



completed plan, ten percent (or 27) did not know how often it had been reviewed. These figures remain consistent for current and former program participants.

Families and providers cited the complexity of the plan – it lacked common language and was not easy to read. As several focus participants commented:

*I want families to be equal partners in the development of the IFSP. For this to truly happen, the time must be spent educating the parents about the services, their choices, and the limitations of the program. Unfortunately, too many times they do not have information about program limitations. As an example, the program generally will not cover genetic testing, yet it is virtually impossible to explain this to the caregiver of a child with congenital anomalies. Another major stumbling block is the program limitations on the purchase of assistive devices or durable medical equipment. We could do a great deal more with the limited funds to meet these needs. This may require families to contribute to paying for the services. This is a very unpopular proposal.*

*My Early Interventionist updates my IFSP with just my family present or the family partner. I understand that everyone who is providing services should be present. It is not fair to my child for me not to be able to ask questions of the different providers. It is often a review by default. I have to take the word of the early interventionist and hope that their responses are correct.*

Another participant felt that the process had worked well for her child and family.

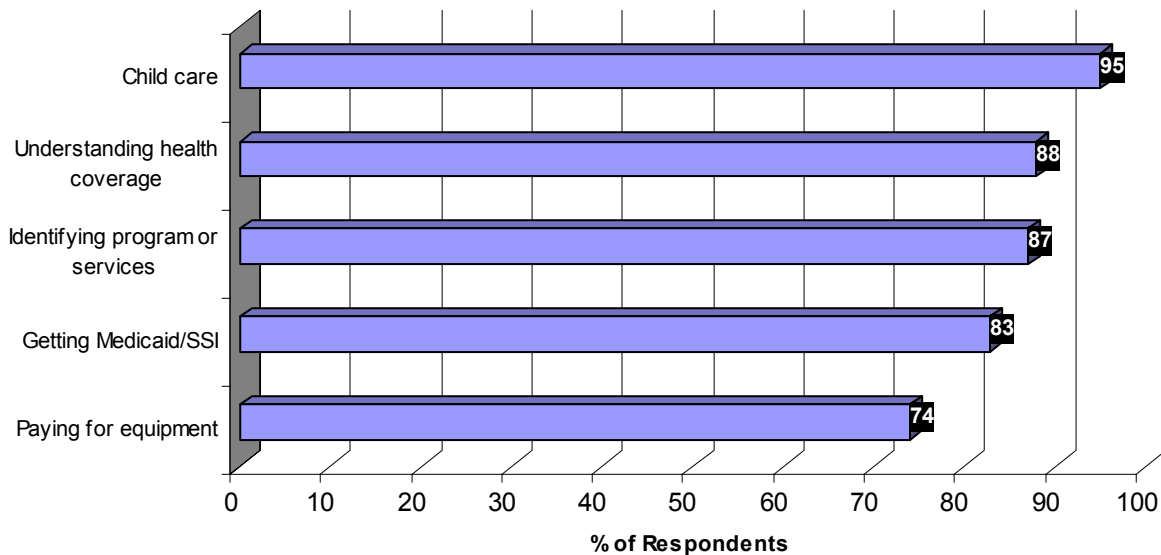
*I always felt like I did not have to sign off on unless the plan was clear. At my meeting the BabyNet Coordinator, Early Interventionist, Family Partner, and Title V nurse was present. Having the meeting at the health department helped with making*

*sure everyone was present for updating the IFSP. My Early Interventionist always made sure to review the reports of providers before the meeting. This helped me to make sure I understood the reports and their recommendations.*

Figure 12 illustrates the number of respondents needing and receiving help with services or activities.

**Figure 12 - Care Coordination**

**Percent of Respondents Needing and Receiving Help with the Following Services/Activities**  
**n = 179**



Approximately forty percent of the respondents (or 179) indicated needing and receiving help with a cluster of services requiring care coordination. This number may underestimate the need for support in these areas. Caregivers participating in the focus groups uniformly indicated that they had not been aware of service or support available through the BabyNet program until their interaction with other parents. This finding indicates the need to extend the opportunities for participants to interact with other caregivers of children in the program.

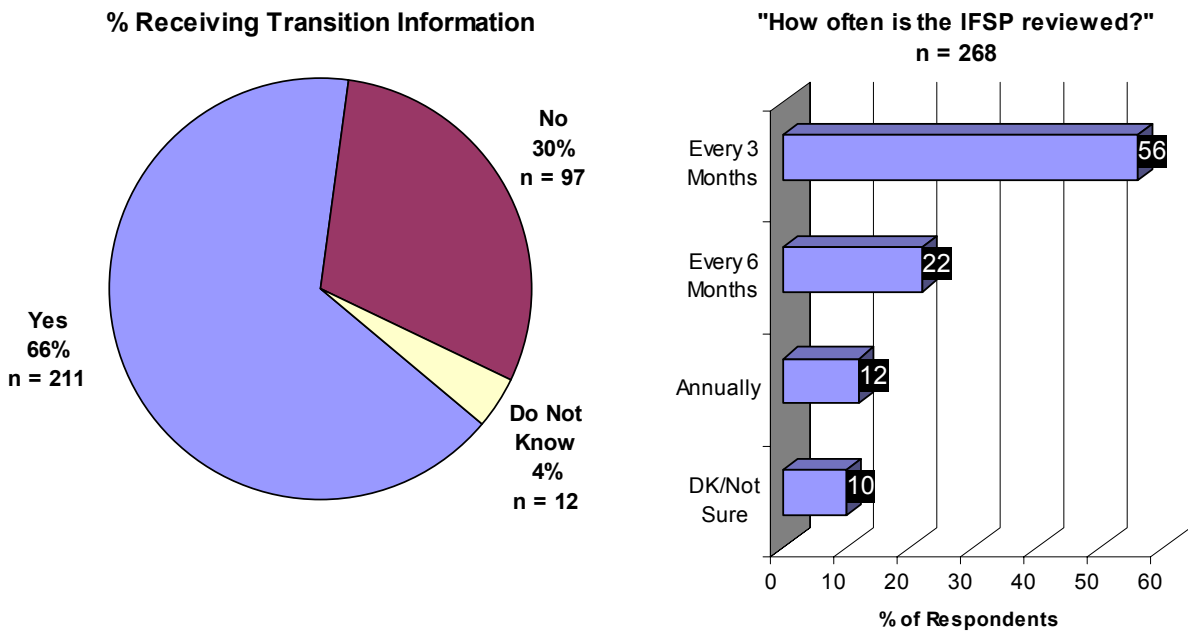
*Early Childhood Transition*

On or before the third birthday, a child moves from the BabyNet to Early Childhood Special Education services and/or other community services. Moving from program to program is called

transition. Ideally, families and service providers walk through this transition together, one step at a time. Questions concerning transition services were limited to caregivers with children eligible to transition to special education services. Three hundred and twenty caregivers met this criterion. Figure 13 depicts the number who reported receiving information about transition services.

### Figure 13 - Transition Services

**“Did you receive information about transition from early intervention to preschool services?”**  
**n = 320**



Providers and caregivers expressed the need to develop a transition process that ensured a child being placed successfully into special education or community service. As several participants commented:

*If my child is not able to transition to other services, then they should be able to stay in the BabyNet program. Due to the timing, my child was without services for three months. The school district did not have summer placements and could not enroll my child without retesting.*

*The Part B program is dependent on the resources available through local school districts. This results in uneven service delivery across the state.*

*The requirement to retest many of the children prevents many children from transitioning successfully into early childhood special education services. School districts should consider granting "presumptive eligibility" pending the completion of evaluations.*

*As a parent, the school district could not explain to me why my child in two weeks could go from needing occupational therapy and physical therapy to no longer needing these services in the early special education classroom. If the goal of both programs is to make sure that a child reaches their full potential, these two programs should have similar criteria for eligibility and services.*

### **General Supervision**

This section of the report examines the findings related to the ability of the state to ensure systems for monitoring, compliance, protection of parent and children. General supervision requires that decisions guiding the delivery of early intervention services be firmly grounded on the collection, analysis and utilization of data from all available sources. The data from key informant interviews and provider focus groups is used to frame this segment of the report.

#### *Monitoring Efforts*

A major theme stressed repeatedly by provider groups and key informants, was the importance of the need to improve the monitoring of the Part C program. Major efforts have been undertaken to address quality assurance, compliance with contractual obligations, and the documentation of the delivery of early intervention services. As one participant describes their experience:

*In the past few months, the self-assessment process combined with new leadership has helped to examine not only our*

*strengths but also areas that need improvement. The fact that this program has survived is a testament to the commitment of the agencies and the staff. The next step is to revamp the training of early interventionist and to eliminate duplication to guarantee true service coordination.*

*State agencies receiving funding to provide service components must be held to higher standards of compliance. The funds need to be used for BabyNet program participants with a direct correlation to the goals of the program. Minimum indirect rates should be in place. No state agency or its sub-contractor should be using more than ten percent of their allocation to cover administrative costs.*

*Sub-contractors should submit to the central office the raw data with completed reports addressing their evaluation efforts. A great need exists to gather information on the efficacy of this program. What has been the impact of the Part C program on reducing costs associated with special education, the number of children requiring long-term care, and the developmental gains resulting from program participation?*

*The lead agency must assume greater responsibility for monitoring both fiscal and service delivery of the Part C program across all state agencies. Perhaps, the time has come to evaluate the efficacy of the existing arrangement and to fine tune services based on the lessons learned and the priorities of the program at the federal and state levels.*

### *Service Integration*

A problem area that was highlighted by participants was that many providers and caregivers are unclear about the roles of the various agencies and partners in the delivery of early intervention services. Respondents gave the following examples:

*The role that physicians should play in this program has never been clear. The primary care needs of the child do not disappear, yet there is this belief that physicians are not active partners in framing the IFSP or determining the referral needs of the child and family. Physicians will remain with the child long after their involvement with the BabyNet Program.*

*There are no clear duties or role differences in the minds of many caregivers between Family Partners, Early Interventionist, and BabyNet Coordinators. As a result, there is a duplication of efforts with large gaps in care coordination and case management that are not being addressed by anyone on the team.*

*The functions of the State Interagency Coordinating Council must reflect the ability to monitor for compliance as a neutral body. The current membership consists of members with vested interest in the success of the program and hold financial ties to the program through contractual obligations. Some parent representatives work as providers for the program and serve as parent liaisons. The appearance of bias is inherent in the current make up of the membership.*

*Children with special health care needs have been left out of the loophole within the Governor's First Steps Initiative. The Part C program is in a position to provide the support, technical assistance, and service integration required to meet the early*

*intervention needs of all children. The lack of involvement of the Part C in a substantial manner needs to be addressed.*

### *Procedural Safeguards*

On a more general level, the need to enhance procedural safeguards was highlighted as an area for improvement.

*Families need to be made aware from day one that they have rights and the procedures to follow to address complaints and due process. They currently do not know that they have choices about the quality of the services they are receiving and the right to provide input on the evaluation of the program.*

*Procedural safeguards will only become a reality when the system for recording services is updated and adequately maintained. The system is outdated with information that more often than not is not accurate or missing fields.*

Another respondent indicated that great strides have been made to identify the shortcomings of the current information system and to implement systematic changes.

*A great deal of credit needs to be given to the current leadership of the Part C program for their willingness to tackle difficult issues. DHEC has finally embraced the role of lead agency for this program. The role of lead agency has not always been well defined or executed within the early years of the program. They have sought and responded to the feedback from the field. They need to be commended.*

### *Program Satisfaction*

Participants indicated high satisfaction with the availability of the program citing the lack of services for this age group without the BabyNet Program. The ability of the program to reach out to children and their families without limitations on income was perceived as a critical

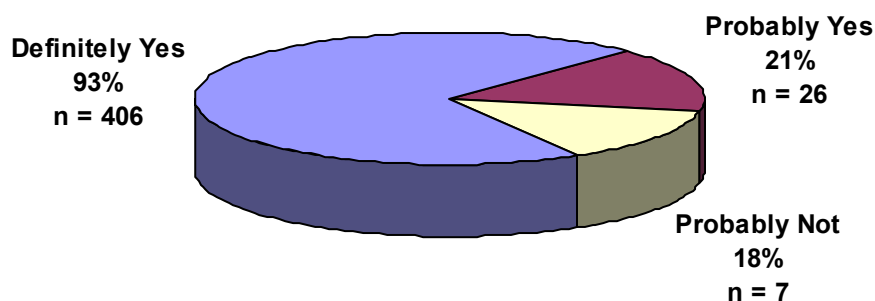
component. Additionally the program emphasis on early intervention has created a statewide atmosphere that values the role of these services in the early stages of the child's life. The emphasis on family participation with support from family advocates was seen as strong commitment to provide family-centered care.

Satisfaction was highly correlated with length of time in the program, the age of the child, and the child's medical needs. As an example, respondents with toddlers receiving only speech therapy services tended to skew the satisfaction levels for all program participants. As a group, their satisfaction levels tended to range between ninety-six and ninety-nine percent of the respondents. Conversely, respondents with children receiving multiple therapeutic services and with complex medical conditions reported lower program satisfaction levels (i.e., eight to twelve percent). Due to high numbers of children receiving single therapeutic services, reported program satisfaction was skewed to reflect a higher average score for the overall BabyNet population.

Eighty-three percent (or 365) of survey respondents indicated being very satisfied with the program. A strong indicator of program satisfaction is the willingness of participants to recommend the program to other caregivers of children with developmental delays and disabilities. Figure 14 points out the expressed program satisfaction of survey respondents as illustrated by their willingness to recommend the program.

**Figure 14 - Program Satisfaction**

**"Would you recommend this program to other families with special health care needs children?"**  
**n = 439**





## Conclusions

The public input effort provided specific information on the strengths and areas for improvement to meet the goals of South Carolina's BabyNet Early Intervention Program. The findings reflect the need to improve coordination across systems of care and the quality of services. The focus groups and key informant interviews corroborate the survey findings and the work of the South Carolina OSEP Monitoring Steering Committee in the identification of the strengths and challenges posed by the design of the current program. Examples, as reported above of systems strengths and challenges, will require a stronger emphasis on the following areas:

1. Child find activities with an emphasis on early identification.
2. Clarification of the roles of providers and state agency partnerships.
3. Enhancement of the training and competency of early interventionists.
4. Implementation of stronger monitoring procedures to maximize limited resources and ensure quality services.
5. Development of safeguard procedures that allow for the maximum involvement of families and providers.
6. Expansion of efforts to integrate the systems of care serving young children with disabilities in South Carolina.

South Carolina's Part C program has moved from the infancy stage of program development into adolescence, effectively helping to bring the issues of early intervention to the forefront of policy discussions on the welfare of children. The strengths of the current system combined with the commitment to refining service delivery systems positions them well for the future. Part C enters the next stage of program development with the skills set necessary to succeed in addressing the long-term needs of young children with developmental delays in South Carolina.

**Appendix A:**  
**Focus Group and Key Informant**  
**Framework**

# Framework for Focus Groups with Caregivers

## *Purpose*

The purpose of the focus groups is to elicit the following information through structured discussions with caregivers of children currently receiving services through the BabyNet Program. The focus groups will attempt to elicit responses to the following questions:

- Who is served within the BabyNet Early Intervention and Preschool Program?
- How did families become aware of the BabyNet Program?
- What services did families receive through the Early Intervention program?
- How, by whom, and in what locations are services provided? Do services differ by locations?
- Do these services meet the needs of the child and their family?
- Which factors hinder or pose barriers for families to receive needed early intervention services?
- What relevant services (e.g., health care, child care, social services) and supports, external to early intervention and preschool program are needed (but not currently provided by you) does your child?
- Which factors facilitate the ability of families to receive needed early intervention services?
- If the early intervention could be redesigned to more effectively meet the needs of children and their families, what things would need to be taken into consideration?

## *Target Population*

Focus Group participants will be recruited from BabyNet-enrolled families that are currently under represented (e.g., middle income families, racial and ethnic minorities, residents of rural and inner city communities) in the current system of care. The recruitment of families will be aided through partnerships with community stakeholders, interagency coordinating councils, and advocacy organizations (e.g., Family Connections, Pro-Parents).

# **Framework for Focus Groups and Key Informants with Service Providers**

## ***Purpose***

The purpose of the focus groups is to elicit the following information through structured discussions with early intervention service providers. The focus groups will attempt to elicit responses to the following questions:

- What is the purpose of the BabyNet Early Intervention Program?
- How do members of your professional discipline support the goals of the Early Intervention program? Do efforts differ by locations, training or affiliation?
- Who is served within the BabyNet Early Intervention and Preschool Program?
- Do early intervention services meet the needs of the children and their families in South Carolina?
- Which factors hinder or pose barriers for families to receive needed early intervention services?
- What relevant services (e.g., health care, child care, social services) and supports, external to early intervention and preschool program are needed and not currently provided?
- Which factors facilitate the ability of families to receive needed early intervention services?
- If the early intervention system were to be redesigned to effectively, meet the needs of children and their families, what factors would need to be taken into consideration?

## ***Target Population***

Focus Group participants and key informants will be recruited from the core professional disciplines identified by Part C as required to meet the needs of early intervention services.

# **Appendix B: Caregiver Survey**

# **Experiences of Families with Children Enrolled in the BabyNet Program**

*A telephone survey conducted by*

**Institute for Families in Society  
University of South Carolina  
937 Assembly Street  
Carolina Plaza - 12th Floor  
Columbia, SC 29208**

**For**

**SC Department of Health and Environmental Control  
BabyNet Program**

**Any questions?**

**Please call Ana López-De Fede at 803-777-9124 for answers.**

## ***Who should answer this survey?***

The birth, foster or adoptive parent of a child with special developmental needs whose child lives at home is under age three and has received early intervention services through the BabyNet Program

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## ***What is early intervention?***

Early intervention services are designed to meet the developmental needs of each child and the needs of the family related to enhancing the child's development. A child and their family become eligible for early intervention services through the South Carolina BabyNet Program.

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*If this **describes** you and your child, we would really value your participation in a survey designed to gain a better understanding of the experiences of families with children who have developmental needs. Your participation will help us to develop services and recommend policies to address the needs of children with developmental disabilities and their families.*

## ***Would you be willing to participate in a telephone survey?***

**If Yes, give instructions.**

### **Instructions:**

- *The survey will take about 30 minutes to complete.*
- *Remember that all questions that ask about "your child" refer to your child enrolled with developmental needs.*

***All your answers will be kept completely confidential. Nothing you tell us will affect any services or benefits for your child***

*If this does not describe your child or you do not want to participate, we apologize for your inconvenience. Thank you very much for taking the time to speak with us.*

## BACKGROUND INFORMATION: CHILD-FOCUSED

1. What is your child's birth date (month, day, and year)?  
\_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
(Month) (Day) (Year)
2. Is your child male or female?  
\_\_\_\_\_ (1) Male  
\_\_\_\_\_ (2) Female
3. Which of the following categories best describes the race or ethnicity of your child?  
\_\_\_\_\_ (1) White or Caucasian  
\_\_\_\_\_ (2) Black or African American  
\_\_\_\_\_ (3) Asian, Pacific Islander, or Southeast Asian  
\_\_\_\_\_ (4) Hispanic, Latino/Latina  
\_\_\_\_\_ (5) Native American, American Indian, Aleut, or Eskimo (6) Multiracial  
\_\_\_\_\_ (7) Other (Please specify) \_\_\_\_\_
4. How did you learn about the early intervention (BabyNet) program? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
5. Approximately how long have you received services from the Early Intervention / BabyNet program? \_\_\_\_\_ Years \_\_\_\_\_ Months (approximately)
  - 5a. How many early interventionist or lead services coordinators have worked your child and family? \_\_\_\_\_ (Indicate the number)

### ***Please tell us about your child's health...***

6. *How would you rate your child's overall health now?*  
\_\_\_\_\_ (1) Excellent  
\_\_\_\_\_ (2) Very good  
\_\_\_\_\_ (3) Good  
\_\_\_\_\_ (4) Fair  
\_\_\_\_\_ (5) Poor



7. What reasons were you given that made your child eligible to receive Early Intervention/ BabyNet services? \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_
8. Does your child have any chronic medical conditions? \_\_\_\_\_ Yes \_\_\_\_\_ No
- 8a. If yes, please tell us which conditions. \_\_\_\_\_  
 \_\_\_\_\_

***Please tell us how your child's medical care is paid for ...***

9. Does your child have a health insurance plan, which is a health plan, health insurance, or Medicaid to help pay for the costs of medical care?
- \_\_\_\_\_ (1) Yes (Go to question 9b)
- \_\_\_\_\_ (2) No (Go to question 9a)

9a. **If your child has no health insurance plan...**

What are the main reasons? **(Please check all that apply.)**

\_\_\_\_\_ (1) Coverage is too expensive

\_\_\_\_\_ (2) Employer does not offer health coverage

\_\_\_\_\_ (3) Health insurance plan through work does not include children or dependents

\_\_\_\_\_ (4) My spouse and I are not eligible for a health insurance plan through work

\_\_\_\_\_ (5) My child was refused coverage

\_\_\_\_\_ (6) My child used up all benefits

\_\_\_\_\_ (7) My child doesn't qualify for Medicaid

\_\_\_\_\_ (8) BabyNet / Early Intervention Program paid for needed services

\_\_\_\_\_ (9) Other reasons (Please describe.) \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**Go to question 10**

9b. **If your child has a health insurance plan...**

Does your health insurance plan pay for the following services?

**(Please check all that apply.)**

- \_\_\_\_\_ (1) Therapies (i.e., Speech, Occupational Therapy)
- \_\_\_\_\_ (2) Home Health Services
- \_\_\_\_\_ (3) Equipment ( e.g., Assistive technology or durable medical equipment)
- \_\_\_\_\_ (4) Prescriptions
- \_\_\_\_\_ (5) Hospitalization
- \_\_\_\_\_ (6) Specialty Care
- \_\_\_\_\_ (7) Other (Please describe.) \_\_\_\_\_

**Go to question 10**

10. Does your child have a primary care provider, that is, a doctor, nurse, or physician's assistant, who provides your child's ongoing medical and well-child care?

- \_\_\_\_\_ (1) Yes
- \_\_\_\_\_ (2) No
- \_\_\_\_\_ (3) Don't know/not sure

***Thinking about the early interventionist ...***

An early interventionist is responsible for providing services and family training to your child and family in your home or a childcare setting.

11. What is the name of your child's early interventionist? (Please tell us the name of the person and the agency for which they work.)

Name \_\_\_\_\_ Agency \_\_\_\_\_

12. How long has your child and family been working with this early interventionist?

- \_\_\_\_\_ (1) Less than 1 year
- \_\_\_\_\_ (2) At least 1 year but less than 2 years
- \_\_\_\_\_ (3) At least 2 years but less than 5 years
- \_\_\_\_\_ (4) Five or more years

13. Based on the needs of your child and family, how is your child's early interventionist doing on ...

	<b>Excellent</b>	<b>Good</b>	<b>Okay</b>	<b>Poor</b>	<b>Don't Know</b>
	<b>(1)</b>	<b>(2)</b>	<b>(3)</b>	<b>(4)</b>	<b>(9)</b>
A. Providing <b>information on the services</b> available through the Early Intervention / BabyNet program.					
B. Giving families enough <b>information</b> about the program at the start to decide whether it was what I wanted for my child and my family					
C. Helping families to <b>understand how the requested information</b> is to be used by the agency					
D. Giving families a <b>choice</b> about when visits are scheduled so they are convenient for my family.					
E. Giving families chances to <b>express their opinions</b> and be the decision maker on the care of your child.					
F. Spending enough <b>time with my child</b> during a visit.					
G. <b>Respecting</b> our culture, ethnic identity, and religious beliefs					
H. Providing suggested <b>activities</b> that are useful in aiding the development of my child.					
I. Helping me to <b>incorporate therapies</b> into everyday routines.					

***Please tell us how your child's care is coordinated ...***

14. Does your child have a written plan that describes his or her needs and services that are to be provided? It is referred to as the Individualized Family Service Plan or IFSP.

- \_\_\_\_\_ (1) Yes, has one (**Go to question 14**)
- \_\_\_\_\_ (2) Yes, has more than one (**Go to question 14**)
- \_\_\_\_\_ (3) No (**Go to question 17**)
- \_\_\_\_\_ (4) Don't know/Not sure (**Go to question 17**)

15. Do you have a copy of this plan?

- \_\_\_\_\_ (1) Yes
- \_\_\_\_\_ (2) No
- \_\_\_\_\_ (3) Don't know/Not sure

16. Were you involved in developing the plan for your child?

- \_\_\_\_\_ (1) Yes
- \_\_\_\_\_ (2) No
- \_\_\_\_\_ (3) Don't know/Not sure

17. How often is this planned reviewed?

- \_\_\_\_\_ (1) Every 3 Months
- \_\_\_\_\_ (2) Every 6 months
- \_\_\_\_\_ (3) Annually
- \_\_\_\_\_ (4) Don't know/Not sure

18. Is there a person, who makes sure that your child gets all the services (i.e., medical, developmental, mental health, therapies, and others) that are needed and that these services fit together in a way that works for you? *{Note: This person may have different titles such as lead service coordinator or early interventionist}*

- \_\_\_\_\_ (1) Yes, have one
- \_\_\_\_\_ (2) Yes, have more than one (How many? \_\_\_\_\_ )
- \_\_\_\_\_ (8) No (**Go to question 19**)
- \_\_\_\_\_ (9) Don't know/Not sure (**Go to question 19**)

18a. What is the name of this person and the agency for which they work?

Name \_\_\_\_\_ Agency \_\_\_\_\_

19. Does this person have a good understanding of your child's health care and services needs?

\_\_\_\_\_ (1) Yes

\_\_\_\_\_ (2) No

\_\_\_\_\_ (3) Don't know/Not sure

20. I want to ask you a couple of questions about the types of activities that they perform in support of your child and family.

<b>Does this person ...</b>	<b>Yes</b>	<b>No</b>	<b>Not Needed</b>	<b>Do Not Know</b>
	<b>(1)</b>	<b>(2)</b>	<b>(3)</b>	<b>(4)</b>
A. Help coordinate your child's care among the different providers and services that help your child?				
B. Help you understand your child's health coverage?				
C. Help you to identify and use other community-based programs or services for which your child may be eligible (for example, respite care, child care, transportation)?				
D. Help you to get other public programs such as, Medicaid, Waivers, or 551 for your child?				
E. Helping families understand the rights and responsibilities that come with receiving Early Intervention / Baby Net program services.				
F. Helping families understand that they need to agree with the services being delivered.				
G. Offer copies of all reports and other documents about your child.				
H. Providing clear information about how to get covered early intervention services and who to call with any questions or problems.				
I. Help you connect with parents who also have a child with special or developmental needs.				

21. If you want, please tell us more about how your child's services are coordinated.

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***Please tell us about your child's care from therapists ...***

22. In the last 12 months, did you have any problems getting the services of physical, occupational, speech, or other therapists that your child needed?

- \_\_\_\_\_ (1) My child did not need any services from therapists (Go to question 22)
- \_\_\_\_\_ (2) My child needed services from therapists and we had no problems getting the service or with the quality of the service (Go to question 21a.)
- \_\_\_\_\_ (3) My child needed services from therapists and we have had some problems getting them. (Go to questions 21a)

22a. Based on the needs of your child and family, did you experience the following problems?

*(Please indicate the type of therapist)*

	<b>P.T</b>	<b>O.T.</b>	<b>Speech Therapy</b>	<b>Other Therapies</b>
A. Getting a <b>referral</b> .				
B. Getting an <b>appointment</b> .				
C. Finding a therapist with the <b>skill and experience</b> to care for my child.				
D. Getting the <b>number of visits</b> to meet my child's needs.				
E. My therapist provided <b>activities</b> for my child to do at home or at the child care center.				
F. <b>Coordination</b> between my child's therapist and other providers.				
G. The <b>health insurance plan would not pay</b> for this type of therapy.				
H. Therapist <b>did not listen</b> to my concerns about my child and the types of activities that would meet their needs.				

***Please tell us how satisfied you are with the services you are receiving through the Early Intervention / BabyNet Program ...***

23. Overall, how satisfied are you with the Early Intervention / BabyNet program for your child?

- \_\_\_\_\_ (1) Very satisfied
- \_\_\_\_\_ (2) Somewhat satisfied
- \_\_\_\_\_ (3) Somewhat dissatisfied
- \_\_\_\_\_ (4) Very dissatisfied

24. Would you recommend this program to other families with children who can benefit from early intervention developmental services?

- \_\_\_\_\_ (1) Definitely yes (**Go to question 24 on this page.**)
- \_\_\_\_\_ (2) Probably yes (**Go to question 24 on this page.**)
- \_\_\_\_\_ (3) Probably not (**Go to question 23a on this page.**)
- \_\_\_\_\_ (4) Definitely not (**Go to question 23a on this page.**)

24a. If not, why not? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

***Please tell us about other services your child needs...***

25. Please tell us about any other services your child needs but you were unable to obtain.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

***We are more than half way done. Can we proceed with the next questions?***

***Transition Services***

If your child is two and a half or older, please tell us about the transition into pre-school services.

**(If your child is younger skip this section, go to question 26)**

26. Have you received information about transition from early intervention to pre-school services?

\_\_\_\_\_ (1) Yes **(Go to question 25a)**

\_\_\_\_\_ (2) No **(Go to question 26)**

26a. Based on the needs of your child and family, how did the Early Intervention / BabyNet program do preparing you for transition out of early intervention services?

	<b>Excellent</b>	<b>Good</b>	<b>Okay</b>	<b>Poor</b>	<b>Don't Know</b>
	<b>(1)</b>	<b>(2)</b>	<b>(3)</b>	<b>(4)</b>	<b>(9)</b>
A. Providing <b>information about options</b> when my child leaves the Early Intervention / BabyNet Program.					
B. Schedule a meeting with school personnel or other services to help you <b>establish a plan for pre-school services.</b>					

26b. In planning for transition, what kinds of things would have helped your child and family? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

***Please tell us about you and your family ...***

***We included the next few questions to make sure we hear from families of all backgrounds. All answers will be confidential.***



27. How are you related to your child with early intervention developmental needs?  
\_\_\_\_\_ (1) Mother  
\_\_\_\_\_ (2) Father  
\_\_\_\_\_ (3) Grandparent  
\_\_\_\_\_ (4) Foster Care  
\_\_\_\_\_ (5) Other (Please specify.) \_\_\_\_\_

28. What is your birth date (month, day, and year)?  
\_\_\_\_ / \_\_\_\_ / \_\_\_\_\_  
(Month) (Day) (Year)

29. What is the highest level of school you completed?  
\_\_\_\_\_ (1) Less than high school  
\_\_\_\_\_ (2) High school graduate or GED  
\_\_\_\_\_ (3) Some college but no degree or Associates Degree  
\_\_\_\_\_ (4) Bachelor's degree  
\_\_\_\_\_ (5) Postgraduate degree

30. What is your marital status now?  
\_\_\_\_\_ (1) Married  
\_\_\_\_\_ (2) Divorced  
\_\_\_\_\_ (3) Separated  
\_\_\_\_\_ (4) Widowed  
\_\_\_\_\_ (5) Never married  
\_\_\_\_\_ (6) Other (Please describe.) \_\_\_\_\_

31. What is your employment status now?  
\_\_\_\_\_ (1) Homemaker  
\_\_\_\_\_ (2) Employed part-time (30 hours/week or less)  
\_\_\_\_\_ (3) Employed full time (more than 30 hours/week)  
\_\_\_\_\_ (4) Unemployed  
\_\_\_\_\_ (5) Not working due to YOUR OWN disability  
\_\_\_\_\_ (6) Other (Please describe.) \_\_\_\_\_

32. What was your total household income from all sources **before taxes** in 1999?

- \_\_\_\_\_ (1) Less than \$10,000
- \_\_\_\_\_ (2) \$10,000-\$19,999
- \_\_\_\_\_ (3) \$20,000-\$29,999
- \_\_\_\_\_ (4) \$30,000-\$39,999
- \_\_\_\_\_ (5) \$40,000-\$49,999
- \_\_\_\_\_ (6) \$50,000-\$59,999
- \_\_\_\_\_ (7) \$60,000-\$69,999
- \_\_\_\_\_ (8) \$70,000 or greater

33. How would you describe the community where you live?

- \_\_\_\_\_ (1) City or urban
- \_\_\_\_\_ (2) Suburban
- \_\_\_\_\_ (3) Farming or rural
- \_\_\_\_\_ (4) Other (Please describe.) \_\_\_\_\_

***AND FINALLY ...***

***We want to send you the results of this survey. If you are interested in receiving a report, please provide us with information on the best way to contact you.***

**We will not share this information with anyone.**

34. Your name? \_\_\_\_\_

35. Your street address? \_\_\_\_\_

36. City or town, state, and zip code? \_\_\_\_\_

***Any other comments ...***

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***Thank you for completing this survey!***

***A copy of the results will be made available to you.***