

**Parent Assessment
of the Service System
for Children with Special Needs
in
Wake County**

A Wake County SmartStart Project
Under the direction of Dr. Henry Lister, Director of Evaluation
And the Local Interagency Coordinating Council

Project management, data collection and report
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DEFINING THE POPULATION

For the purpose of this study, children with special needs are defined loosely as children who have or are at risk for developmental delays or disabilities, behavioral, emotional or mental health concerns, atypical development, or chronic health problems. Targeted children were between the ages birth through five years with parents who identify their child as having special needs. These children are eligible or receive services from agencies that serve children identified through Early Intervention (Infant/Toddler Services), Wake County Public School System, or private therapists (OT, Sp/L, PT or mental health/behavioral).

It is almost impossible to develop an unduplicated count of children who are currently accessing this service system. Local agencies collected and reported data about the children served differently according to child's age and lead agency or funding source requirements. The next paragraph gives an account of the numbers of children served by the public system as reported to the state. This does not include children who receive private therapy or counseling services outside the parameters of Early Intervention and Wake County Public School Services.

Wake County has a total of 41,896 children under age five.¹ During the 1999/2000 fiscal year, 2660 children received services through Child Service Coordination and 334 received Infant/Toddler services.² According to the April 1, 2000 head count 654 children received services through the Wake County Public School System Preschool Program.³ See the chart below for comparisons with statewide numbers of children served within these three program areas. The percentage of the population for the Infant/Toddler program is based on numbers of children birth to age three (Wake County 25,035; NC 308,261), and Public School Preschool Services are based on the number of children between three and five years old (Wake County 16,861; NC 206,617).

Table 1

Program	Number of children served in Wake County	Percentage of Wake County population	Number of children served statewide	Percentage of population⁴
Child Service Coordination	2,660	6.3%	51,427	10%
Infant/Toddler Services	334	1.3%	6,986	2.3%
Public School Preschool Services	654	3.9%	12,074	5.8%

¹ Certified estimate, NC population as of 7/1/99.

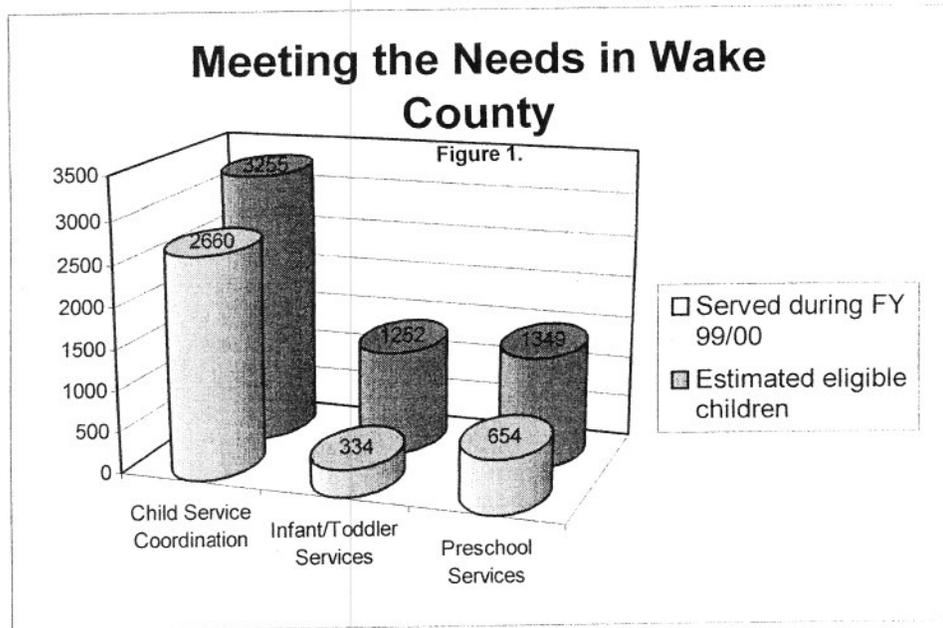
² NC DHHS, Division of Early Intervention and Education FY 2000 Infant-Toddler count

³ Department of Public Instruction 4/1/99 head count including pre-k five year olds

⁴ Certified estimate, NC population as of 7/1/99: total under 60 months 514,878.

Frank Porter Graham researchers estimate that a much higher percentage of children are eligible and should be receiving early intervention services. Shown in the chart on the right, Child Service

Coordination's estimated population is at 13% while Wake County is serving 6.3%. According to Dr. Gloria Harbin Infant/Toddler services should set a goal to find and serve 5% of the general population by the year 2004, and 13% by 2009.⁵ The chart to the right shows the estimated population of children at 5% (1252). Dr. Harbin also recommends Preschool Services should be serving 5% - 8% of the general population yet currently Wake County is serving only 3.9%.



⁵ Harbin, Gloria (1999). North Carolina's Early Intervention System for Children Ages Birth-through-Five Years: A Comprehensive Review. Bordeaux Consulting, Inc. 2001

DATA SOURCES and COLLECTION PROCEDURES

The Local Interagency Coordinating Council (LICC) subcommittee provided a list of agencies and contacts to assist with distribution of questionnaires and materials advertising the parent forums. A joint letter from Wake County Smart Start and the LICC supporting this project was mailed to each agency with a follow-up phone call to gather estimates of children served and answer any questions about the data collection process or purpose of the project. The targeted group included parents who are Wake County residents with at least one child under age 6 who has special needs. Agency staff received specific instructions for material distribution and sampling, followed by phone calls to clarify instructions and answer questions.

Parent Forums

Detailed descriptions of parent experiences with the service system for children with special needs in Wake County were obtained through five (5) small group forums, designed for 10 to 15 participants, and led by the same facilitator. While the facilitator provided a loose structure for the meetings, parents were allowed to lead the discussions within the parameters of the forum outline (see outline in appendix C). The facilitator used searching questions and prompts to draw out the participation of each parent, however, participants were not required to respond at any particular level. Parents were asked to call and register for the forums, indicating the time and location of the forum they wanted to attend and any needs for child care or transportation assistance. Each family was given a \$10 gift card to Wal-Mart in appreciation of their participation. Parents signed a consent/confidentiality form at the beginning of each session, and all families were asked to complete a parent questionnaire.

To advertise forums, packets of flyers and invitations were delivered to 40 agencies that agreed to assist in the distribution of over 3000 flyers to families across the county. In addition, public notices were given through local television and radio stations, and flyers were posted throughout agencies serving young children.

Parent Questionnaires

Parent Questionnaires were used to access information and opinions from a broader array of parents who are currently using services for their child with special needs. The questions were designed to be easily coded leaving more descriptive responses to be gathered through forums. The LICC subcommittee, evaluation staff and consultants worked together to develop the questionnaires, which were then reviewed by the database consultant prior to the final revision.

Pilots were given to 10 parents, of which 5 responded, and included estimates for completion time and opportunities for comments or questions regarding difficulties with particular items. Questions concentrated on services received in the past year, difficulties in accessing services, helpfulness of services, parental empowerment, communication between service providers and parents, child care arrangements and difficulties obtaining and maintaining child care, inclusive services, and demographics about the child and family, in addition to one open ended question (see appendix B for full survey instrument).

Twenty-nine agencies received packets of questionnaires to be distributed. Each agency was instructed to randomly select a sample of 40% of the population of children served who meet the target population criteria. Each agency packet contained instructions for questionnaire distribution and the select number of questionnaires with attached parent cover letters, incentive coupons and pre-addressed, stamped return envelopes. Parents were asked only to complete one questionnaire even if their child receives services from multiple agencies. Agencies received as many as four follow-up phone calls to encourage full distribution of questionnaires.

While most questionnaires were distributed by hand during clinic appointments and through home visits or other one-on-one contact with parents, others were distributed via the child in instances where services were delivered through a classroom setting. A few agencies were only able to distribute

questionnaires through clinic waiting rooms. Agency staff distributed questionnaires as randomly as possible, however in some cases it was necessary to choose specific parents based on their ability to understand and answer the questions independently and to return the survey. Parents with cognitive or mental health needs or language barriers may have been excluded in some cases.

FINDINGS

PARENT FORUMS

Forums were used as a method to gather detailed descriptions of parent experiences in obtaining and working with service providers to meet their child's needs in Wake County. Parents, grandparents and foster parents compassionately and emotionally opened their lives to each other and the consultants. While they shared their stories, they also shared pains and joys, tears and support for each other and for other parents who for whatever reason did not choose to participate. At the end of each forum, several parents chose to exchange phone numbers and made plans to keep in touch, continue building relationships and supporting each other. See appendix D for more detailed descriptions of some of the family situations.

Forums were held at the following locations and times:

1. November 30, 2000 (Optimist Park Community Center, evening) – 7 parents representing 6 families attended.
2. December 2, 2000 (Tammy Lynn Center, morning) – 19 parents representing 15 families attended.
3. December 5, 2000 (White Plains United Methodist Church, evening) – 10 parents representing 8 families attended.
4. December 7, 2000 (Wake County Human Services, morning) – 9 parents representing 9 families attended.
5. December 9, 2000 (Wake County Public Library in Knightdale, morning) – 10 parents representing 9 families attended.

Forty-three of the 47 families who attended completed a parent questionnaire, and four parents had already completed the questionnaire through a service agency. Of the 43 families who completed the questionnaire, 81% began receiving services when their child was under age 3. The current age of children with special needs represented was more equally distributed with 31% between 0-2, 45% between 3-5 and 24% above age 5. Parents with children over age five were asked to respond according to services they received when their child was between the ages birth to five years.

Types of special needs represented throughout parent forums included:

Adaptive behavior disorders		
ADHD	Fetal Alcohol Syndrome	Multi-symptom without diagnosis
Anxiety disorder	Fragile X syndrome	Physical disabilities
Autism	Heart condition	Sensory processing disorder
Cerebral Palsy	Hydrocephalus (internal & external)	Severe allergies
Chromosomal disorders	Language impairments	Spina Bifida
Developmental delays	Learning disabilities	Visual impairment
Difficulty with social skills		
Epilepsy	Low muscle tone	

Parents were asked to talk about strengths and concerns throughout the process and were allowed flexibility to lead the discussions across three major areas of experience:

- Access to services
- Personal Power
- Family Support

If time remained, parents were given an opportunity to list the one thing that would be their highest priority for change (Magic Wand). Themes emerged in each area across forums. Below the most prominent themes are shown for each topic area.

Access to services

Concerns or needs relating to access

Themes discussed during all five forums:

- The wait for services is long, often with no follow-up while you wait
- Service options need to be better publicized; it's hard to know what to ask for; need a single source for information
- Pediatricians were not helpful ("wait & see") Need to educate pediatricians on the resources and urgency to access services early
- Parents have to push to get what is needed

"Our pediatricians said for us not to worry, boys just start talking later."

Themes emerging across four of the five forums:

- Making the right contact makes a difference – sometimes the direct service agency, a knowledgeable therapist or developmental preschool can help you get through the process

Themes emerging across three of the five forums:

- Transitions are difficult – anytime you change from one provider to another
- Parent was unable to obtain the amount of therapy services that parent felt their child needed
- Paperwork is overwhelming
- It is difficult to access services when you are a newcomer to the county or when your child is not identified at birth (earlier diagnosis = better access to resources)
- Parents need support and information at the onset – parents are grieving and overwhelmed when initially trying to access services
- Cost of services is difficult and insurance doesn't pay enough

"It's a full time job to get services for your child."

Strengths encountered while accessing the service system

Across all five forums, parents relayed general positive experiences with specific services, agencies or programs. These are listed below.

Positive experience reported with a specific service or agency:

Benson Memorial
CAP
Community Partnerships Inc.
CSC
DEC
Early Intervention
First in Families
Frankie Lemmon
Governor Morehead

In-home services
Learning Together
LICC
OT
Pediatrician
Project Enlightenment
SICC
Smart Start screenings in child care

Social Worker
Tadpole Lending Library
Tammy Lynn
TEACCH
UCP
Wake County Audiologist
Wake County Public Schools

Only one other theme emerged around service strengths:

- Friends or other parents helped get connected to services (emerged across three of the five forums)

"... has been a saving grace in helping us get in contact with other parents."

Parents' perceptions of personal power

Themes emerged across all five forums:

- Parents must be proactive
- Parents need training, knowledge and information to be advocates

Themes emerged across four of the five forums:

- We are all in a different place – some parents are more able to be proactive and fight for what they need, others don't know where to turn or have few personal resources
- Building relationships with doctors, hospital and service providers helps advocacy (don't get labeled a "difficult parent")
- Parents have little power with Wake County Public School System services (felt left out of IEP process)
- Income/affordability = choice
- Researching, searching for resources and completing paperwork takes an enormous amount of time

"I don't want to be labeled a difficult parent." . . . "You have to fight for what is best for your child." . . . "But sometimes you don't know what to fight for."

Themes emerged across three of the five forums:

- It is hard to be proactive when you are overwhelmed; parents need support

Family support

Listed below are the shared themes and the corresponding forums in which they appeared.

What helped the most?

Themes emerged across all five forums:

- Getting connected with other parents who have children with special needs and are going through the same things
- Church, prayer, spirituality, meditation, support from priest

Themes emerged across four of the five forums:

- Child's successes, smiles, the love for your child

Themes emerged across three of the five forums:

- Neighbors & friends – having someone to talk to
- Specific agency listed: Community Partnerships, Inc., Early Intervention, Project Enlightenment, Respite

Themes emerged across two of the five forums:

- Increased knowledge, understanding

What have you needed or what was difficult?

Themes emerged across three of the five forums:

- Time

Themes emerged across two of the five forums:

- Extended family can't handle it or they are not supportive
- Money

Magic wand

**If you had a magic wand and could change one thing, what would it be?
(Question asked only for forums 1,2 & 5)**

Themes emerged across all three forums:

- Services without waiting – immediate access

- Funding for services, insurance that pays
- Themes emerged across two of the five forums:
- One place to go for all information – resources and services options

PARENT QUESTIONNAIRES

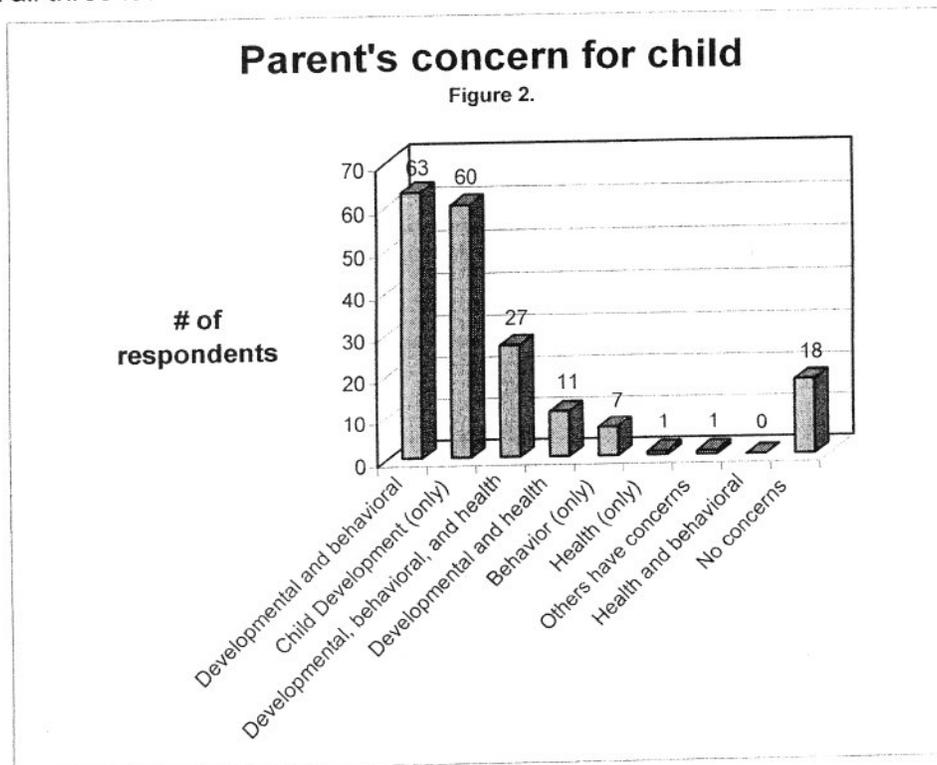
Approximately 592 parent questionnaires were distributed, with 188 returned, yielding an estimated response rate of 32%. The response rate is estimated because three agencies were unable to report the final number of questionnaires distributed.

Demographics (See Appendix A, Tables 2-8)

Questionnaire respondents were primarily white (69%) and living in two parent households (80%). The age of the average child with special needs represented through questionnaires is three and three-fourths years, with services beginning at age two. Taking a closer look, 21% of representative children are currently between the ages birth through two years, 63% are between three and five years, and 15% are above age five with the maximum age reported at seven years. Sixty-one percent of respondents' children began receiving services prior to age three, and 39% began receiving service between the ages three and five years.

Family incomes range from under \$31,500 (23%), between \$31,501 - \$73,500 (41%) to above \$73,501 (35%). The median family income for Wake County is \$55,000, while the median income range for this sample is between \$52,501-\$63,000.

The chart below shows parental reports of concerns for their child. Most parents were concerned about their child's development and behavior (34%) or just development (32%). Very few had only health or only behavioral concerns. Fifty-four percent had two of the three concerns and 14% of parents were concerned about all three issues.



Area of residence by zip code showed families who completed questionnaires are spread fairly evenly across the county. Five regions were selected as shown below with number of respondents per region.

Table 9

Zip Code Region	Zip Codes contained in region	Towns contained in region (all areas contain some of Raleigh)	Respondents per region (% of total respondents)
East Wake	27571, 27616, 27604, 27545, 27591, 27597	Rolesville, Knightdale, Wendell & Zebulon	27
North Wake	27612, 27613, 27609, 27615, 27614, 27587, 27572, 27617, 27629	Wake Forrest	42
Central Raleigh	27607, 27605, 27608, 27601, 27610	Raleigh	30
West Wake	27560, 27512, 27513, 27502, 27511, 27562	Holly Springs, Apex, Cary & Morrisville	44
South Wake	27529, 27603, 27592, 27526, 27540, 27606	Garner & Fuquay Varina	39

Services received in the past year (See Appendix A, Tables 10-13)

Parents were asked to check the specialized and family support services they have used in the past year. This was then analyzed in relationship to the age when their child began receiving service and the current age of their child as well as by family income and residential zip code region.

Specialized Services

Specialized Services include:

- Special education and/or developmental instruction
- Physical therapy
- Occupational therapy
- Speech/Language therapy
- Vision services
- Audiological services
- Psychological services
- Specialized equipment
- Behavioral counseling

- Speech/Language therapy was the most widely used service (79%), followed by Special Education (57%), Occupational therapy (47%), Audiological services (34%) and Physical therapy (31%).
- Children who began services at an earlier age are more likely to be receiving some specialized therapies. For example – 65% of children who began receiving services between 0-2 are receiving OT services while only 20% of children who began services between 3-5 are using that service. Similarly with PT services: 49% of children who began services before age 3 received PT while only 4% of children who began services after age 3 are using that service. This does not stand true for Speech/Language therapy or other specialized services.
- Speech/Language Therapy and Occupational Therapy services showed a higher use rate for middle and higher income families, while Physical Therapy showed the highest use rate for middle-income families.
(Income ranges: < \$31,501 = low; \$31,501-\$73,500 = middle; >\$73,500 = high)
Speech/Language: 72% low, 78% middle, **89% high**
Occupational Therapy: 26% low, 51% middle, **55% high**
Physical Therapy: 23% low, **36% middle**, 29% high
- Most parents reported using 2-3 services across all five regions of the county.

Family Support Services

Family Support Services include:

Resource materials

Resource center or library

Internet resources

Child Service Coordination

Social Work Services

Respite care

One to one parent support link

Parent support group

Parent education class or workshop

Individualized child development instruction

Family counseling

Child care subsidy

- Child Service Coordination was the most widely used Family Support service (41%) followed by Resource materials (40%), Individualized Child Development Instruction (33%), Internet resources (25%) and Resource centers or libraries (21%).
- Higher income families are less likely to be using some services:
(Income ranges: < \$31,501 = low; \$31,501-\$73,500 = middle; >\$73,500 = high)
Child Service Coordination: **56% low**, 46% middle, 24% high
Social Work Services: **44% low**, 18% middle, 8% high
- Most Family Support services were more likely to be used by middle-income families, followed by high-income families.
Resource materials: 30% low, **44% middle**, 37% high,
Individualized child development instruction: 21% low, **42% middle**, 32% high
Resource center or library: 14% low, **28% middle**, 16% high
One-on-one parent support link: 12% low, **25% middle**, 18% high
Parent education class or group: 14% low, **21% middle**, 19% high
Parent support group: 2% low, **25% middle**, 21% high
Respite care: 5% low, **22% middle**, 15% high
- Most parents reported using 2-3 family support services across all five regions, however, the Central Raleigh region showed the highest use rate from 2-4 services.

Accessing services (difficulties and most helpful – See Appendix A, Tables 14-24)

Parents responded to a checklist of items that were most helpful regarding specialized and family support service in general. In addition, parents were asked to indicate any difficulties they encountered

as they tried to access services. Difficulties were analyzed in relationship to the type of services used, and family income, and residential zip code region.

Specialized Services

HELPFUL – Parents reported the following as the **top three items** that make Specialized Services **most helpful**:

- Parents felt providers were friendly and respectful (73%).
- Parents felt they received the help they needed (66%).
- Parents felt the information they received was clear (52%).

The three items that were **reported the least** as making Specialized Services helpful:

- Least reported: Services were covered by insurance (32%).
- 2nd least reported: My child was helped quickly (36%).
- 3rd least reported: Service providers followed up to see how my child was doing (38%).

DIFFICULTIES – The top three difficulties parents reported in using or trying to access Specialized Services are listed below in order by the number of total responses across services:

- Wait for services
- Cost for services
- Inconvenient location

Table 15

A	B	C	D	E	F = (E/C)	G	H	I = (H/C)
Type of service	Total # who used service	# who reported at least 1 difficulty	#1 difficulty reported and # that indicated that difficulty		% of those who had a difficulty	#2 difficulty reported and # that indicated that difficulty		% of those who had a difficulty
Speech/Language Therapy	149	55	Wait time	26	47%	Cost	18	33%
Special Education	108	35	Wait time	15	43%	Location	14	40%
Occupational Therapy	88	28	Cost	11	39%	Location	9	32%
Audiological Services	63	9	Wait time	4	44%	Lack of family support/Location	2	22%
Physical Therapy	58	13	Cost	6	46%	Not eligible	3	23%
Vision Services	40	8	Cost	2	25%	Location	2	25%
Specialized Equipment	27	14	Wait time	8	57%	Cost	4	29%
Psychological Services	22	7	Availability	3	43%	Cost	2	29%
Behavioral Counseling	14	6	Wait/no child care	3	50%	Availability	2	33%

- Difficulties analyzed across family income showed cost and wait for services were most reported among middle-income families.
(Income ranges: < \$31,501 = low; \$31,501-\$73,500 = middle; >\$73,500 = high)
Cost: 5% low, **26% middle**, 10% high
Wait: 16% low, **29% middle**, 15% high
- Transportation, difficult to contact service providers, and inconvenient hours of operation were more difficult for lower income families than for middle or high-income families.
Transportation: **19% low**, 6% middle, 3% high
Difficulty contacting providers: **12% low**, 7% middle, 3% high
Inconvenient hours: **14% low**, 0% middle, 5% high

- Overall, higher income families showed fewer difficulties than middle or low-income families.
- Families living in the Central Raleigh region indicated difficulty with transportation and availability of Specialized Services more often than families from other regions. Families living in the Southern Wake region indicated difficulty with cost for Specialized Services more often than families from other regions.

Table 19

Area of Difficulty	East Wake	North Wake	Central Raleigh	South Wake	West Wake
Transportation	2 (7%)	1 (2%)	5 (17%)	4 (10%)	4 (9%)
Availability	2 (7%)	2 (5%)	6 (20%)	2 (5%)	0 (0%)
Cost	3 (11%)	7 (17%)	5 (17%)	10 (26%)	4 (9%)

Family Support Services

HELPFUL – Parents reported the following as the **top three** items that make **Family Support Services** most helpful:

- Parents felt providers were friendly and respectful (47%)
- Parents felt they received the help they needed (45%)
- Parents felt the information they received was clear (37%)

The three items that were **reported the least** as making Family Support Services helpful:

Least reported:

- Services covered by insurance (15%)
- 2nd least reported: Service providers followed up to see how my child was doing (27.6%)
- Tied for 2nd least reported: Service provided in a convenient location (27.6%)
- 3rd least reported: Received help quickly (28%)

DIFFICULTIES – the top three difficulties reported in using or trying to access Family Support services are listed below in order by the number of total responses across services:

- Wait for services
- Inconvenient location
- Difficulty contacting service providers

Table 21

A	B	C	D	E	F = (E/C)	G	H	I = (H/C)
Type of service	Total who used the service	# who reported at least 1 difficulty	#1 difficulty reported and # that indicated that difficulty		% of those who had difficulty	#2 difficulty reported and # that indicated that difficulty		% of those who had difficulty
Child Service Coordination	77	13	Wait	7	54%	Availability/ difficult to contact	2	15%
Resource Materials	75	11	Wait	3	27%	Location/cost/ difficult to contact	2	18%
Individualized Child Dev. Instruction	62	11	Wait/ disrespectful treatment/ availability	5	45%	Eligibility	2	18%
Internet resources	47	6	Wait/difficult to contact	2	33%	Unable to determine #2 difficulty		
Social Work Services	40	8	Wait	5	63%	Eligibility	3	38%
Resource Center or Library	39	14	Location	7	50%	Hours	3	21%
Parent Education Class/Group	36	16	Location	7	44%	Child Care for siblings	5	31%
Parent Support Group	36	12	Location	4	33%	Difficult to contact	3	25%
One to One Parent Support Link	36	8	Wait/difficult to contact	3	38%	Availability	2	25%
Respite Care	27	15	Wait	8	53%	Availability/ cost	4	27%
Child Care Subsidy	26	13	Availability/ Wait	4	31%	Unable to determine #2 difficulty		
Family Counseling	12	10	Wait/Child care for siblings	3	30%	Cost	2	20%

- Analysis by income showed again that higher income families are less likely to indicate difficulties, especially in the area of wait for services.
(Income ranges: < \$31,501 = low; \$31,501-\$73,500 = middle; >\$73,500 = high)
Wait: 12% low, 15% middle, **3% high**

General experience receiving services and relationships with service providers (See Appendix A, Tables 25-27)

- A. Service providers talk with you about the needs and strengths of your child.
80% of parents reported Always or Often.
- B. Service providers talk with you about your service options.
58% of parents reported Always or Often.
35% of parents reported Sometimes.
- C. Service providers talk with you about your legal rights.
36% of parents reported Always or Often.
58% of parents reported Sometimes or Never.
20% of parents reported Never.
- D. You are able to choose the amount of involvement that you, as a parent, have in deciding the service goals for your child and family (such as developing the IFSP, IEP or other goal plan).
72% of parents reported Always or Often.
Parents of children between ages 0-2 more often reported Always
Parents of children 3->5 more often reported Sometimes or Never.
Parents of children 0-2: **67% always**, 18% often, 10% sometimes, 0% never
Parents of children 3->5: 47% always, 22% often, **19% sometimes, 6% never**
- E. You are able to choose the amount of involvement that you as a parent have in deciding where and from what agency your child will receive services.
60% of parents reported Always or Often.
Parents of children between ages 0-2 have higher percentages for Always
Parents of children 3->5 have higher percentages for Never.
Parents of children 0-2: **51% always**, 18% often, 28% sometimes, 0% never
Parents of children 3->5: 34% always, 24% often, 23% sometimes, **13% never**
- F. You are in agreement with service providers on the type of services your child needs.
80% of parents reported Always or Often.
Parents with older children reported Sometimes or Never slightly more often than parents with younger children.
Parents of children 0-2: 64% always, 26% often, 8% sometimes, 0% never
Parents of children 3->5: 52% always, 26% often, **19% sometimes, 2% never**
- G. You are in agreement with service providers on how often your child receives services.
70% of parents reported Always or Often.
Parents with older children reported Sometimes or Never slightly more often than parents with younger children.
Parents of children 0-2: 51% always, 36% sometimes, 13% often, 0% never
Parents of children 3->5: 43% always, 23% often, **25% sometimes, 6% never**

Child care

Twenty-three (12%) respondent parents indicated their child has been asked to leave or refused child care due to their special needs – 11 (48%) due to behavioral issues and 12 (52%) due to health or developmental issues.

Of those 23, only 6 currently attend a child care center.

Table 28

Type of care currently using	# of children who have previously been asked to leave or refused child care	% of 23
Cared for by parent in home	12	52%
Child care center	6	26%
Day care home	1	4%
Home of relative	1	4%
Did not respond to current child care question	3	13%

- One hundred three (60%) parents reported they don't use or need child care because the parent cares for their child in the home.
- Only 5 (14%) children between 0-2 attend a child care center while the remaining 13 (35%) are cared for by a relative, nanny or family child care home provider.
- Thirty-four (31%) children 3-5 attend a child care center and only 7 (6%) are cared for by a relative, nanny or family child care home provider

Inclusion

Eighty-one (46%) parents of children 0-5 indicated it was Very Important that their child is served in an inclusive environment. One hundred eleven (59%) respondents felt it was either Very Important or Somewhat Important that their child is served in an inclusive environment. These numbers were analyzed by current age and age when services first began. There was less than 5% difference in the two groupings.

Only 10% of parents felt it is very important for their child to be served in an environment with other children with special needs. Twenty-five percent indicated that it doesn't matter or they have no opinion.

Insurance and Expenses

Ninety-seven percent of children are covered by health insurance - 71% through an employer, 21% Medicaid, 7% self-pay private and 2% Health Choice. Only 6 parents reported their child is not covered by health insurance.

Forty-nine (28%) parents reported that they pay between \$101 and \$500 per month for special equipment, services or medications specifically for their child's special needs. While, 15 (9%) indicated paying over \$500 per month. Some parents included comments indicating they included child care cost or private insurance premiums in this amount.

Overall feeling about services

Below, listed in order, are grouped parent responses to the survey question: "Overall, how do you feel about services for children with special needs in Wake County?"

Table 29

Strengths identified from parent responses	Total	Responses with children 0-2	Responses with children 3->5
Pleased with services in general. Some specific services mentioned: Therapists, Project Enlightenment, Early Intervention, Child care, CSC	109	18	
Preschool services, Wake Co. Public School Services, DEC, Tammy Lynn, Governor Morehead, Baileywick Elem., Durant Elem., Frankie Lemmon, Learning Together, Contained classroom, Inclusive setting, pediatrician, in-home therapist, psychological services			91
People (service providers) are nice and helpful	10	4	6
Impressed with the number of services, resources and support options available	5	2	3
Child has shown improvement	4	0	4
Pleased with teachers	4	1	3
Evaluations were accurate and services are of high quality	3	0	3
Appreciate flexible schedules	2	1	1
Child was served quickly	1	0	1
Thankful that services are free	1	0	1

Table 30

Concerns identified from parent responses	Total (164)	Responses with children 0-2 (31)	Responses with children 3->5 (133)
✓ Wait for services	20	3	17
★ Limited resources – overall need more services, respite for medically fragile, play group, parent support	15	4	11
✓ Cost of services – lack of insurance coverage	9	3	6
General comments of discontent	9	0	9
Parents have to push to get what we need	8	2	6
Need more support for inclusive environments	7	0	7
Need to better publicize what services are available, it's hard to know what to ask for	7	0	7
Need to increase the amount of services/service time that child receives	5	0	5
Service providers have a negative attitude	3	1	2
Driving distance to access services is too far	3	0	3
Need to improve child care quality and availability for children with special needs	3	2	1
Services need to be less fragmented – need summer services, merge responsible agencies for nonstop continuation of services	3	0	3
Parents need more say in determining services and setting	1	0	1

RECOMMENDATIONS

The wait for services and the gap between the estimated eligible population and the numbers of children being served indicate the system lacks capacity to meet service demands. Throughout this study, parents expressed overwhelming frustration in trying to get connected, knowing whom to call, being told to “wait and see”, waiting months for services to begin after their child’s needs have been identified and the mounds of duplicative paperwork required from each agency. However, there were very few concerns expressed either about the way services were delivered or the quality of services once they began. In fact, responses to the open-ended survey question were mostly positive, naming many agencies and programs that are providing extra special care for a child.

It is overwhelming for parents as they face the difficulties of finding the appropriate service in an inherently complicated system of public and private providers, where the rules change as your child ages out of one program into another. In the survey, parents reported often not being informed of their legal rights (across ages) and having little personal power in determining services for their child through the Public School System. The change in eligibility criteria and the change in overall system philosophy that happens when a child turns three and transitions from Infant/Toddler services to Preschool services can be difficult for parents to accept. It is even more difficult if they do not completely understand the changes or if they are not prepared for the changes well in advance. From birth through age two, services are provided through a holistic, developmental approach, including the family in the service plan. At age three, the focus turns to education and becomes more structured, focusing totally on the child. Therefore, not only is it difficult to understand service options at the onset of identification, parents and children have to adapt to a new way of doing things when transitioning to Preschool Services.

Ultimately, even the best service delivery system cannot provide everything a family needs without enhanced support services. Grieving families, families in crisis, families who are trying to understand the complicated aspects of a diagnosis or struggling with the lack of an appropriate diagnosis . . . families like these need to be nurtured, respected, supported and allowed to strengthen and assume control. It is not entirely negative that parents report having to advocate or fight for the services their child needs. One parent from a focus group reported the struggle has made her a better parent. However, parents should not be left to advocate and struggle alone.

RECOMMENDATIONS:

- **Increase service capacity** without hindering the current quality of services provided. Multiple strategies may be used over the short and long term, including but not limited to:
 - Lobbying for additional funding through state and federal sources.
 - Using foundation grants and other private funding sources (including donor resources) to increase program service capacities and bring new, creative programming into Wake County.
 - Assessing the service system for collaboration opportunities.
- **Increase the efficiency by which parents can learn about and access the service system.** This includes enhancing publicity and communication about service options, legal rights and access procedures. Some strategies may include:
 - Identifying a single initial contact point for parents to call for information about services for a child with special needs: Child Service Coordination and Wake County Human Services (Early Intervention) staff are familiar with the broad array of services available for families even beyond age three. Highly publicize this contact and provide information beyond public service options and across ages birth through five years. Information should also be available through this resource about parent’s legal rights and parent support services.
 - Developing a new parent orientation for children 0-2 and 3-5 to describe how the service system is designed, provide resource information for public, private and support services and have program staff available to answer questions. This orientation could be held monthly in different

locations across the county, with alternating day and evening meetings to meet the various needs of families.

- Enhancing transition services to include early parent education about the system changes from Infant/Toddler to Preschool services, advocacy techniques, and alternative service options.
- Collaborating with State efforts to educate local Pediatricians and other health care providers about the importance of early identification and quick access resources for families. New relationships, stronger communication links and tools to help them do their jobs better are necessary to change the way medical professionals address identification and referral.
- **Provide the support families need.** Again many strategies may be employed to enhance support services for families, including:
 - Increasing parent mentoring programs and one on one parent links such as Parent to Parent.
 - Increasing education and support groups for parents and siblings of children with special needs.
 - Increasing opportunities for parent involvement in program activities that connect with other families, including opportunities for families to provide support for each other through agency programs.

LIMITATIONS:

These recommendations focus on the outstanding needs recognized by parents and do not address all the needs identified throughout this report. This is designed merely as a starting point for further planning efforts and should be considered thoroughly along with other needs assessment data and planning team responses. Recommendations here are based only on parent input and do not include any analysis of existing services, resources or service provider opinions.

APPENDIX A

Demographic: Tables 2 – 8

Table 2: Race by Age of Child

Race	Children between 0-2	% of 110	Children between 3-5	% of 67	All Children 0-5	% of 177
White	80	73%	43	64%	123	69%
Black	20	18%	18	27%	38	21%
Asian	3	3%	2	3%	5	3%
Other	6	5%	4	6%	10	6%
Hispanic	4	4%	1	1%	5	3%

Table 3: Household Structure by Age of Child

Household Structure	Children between 0-2	% of 108	Children between 3-5	% of 70	All Children 0-5	% of 178
Mother & Father w/ children	86	80%	56	80%	142	80%
Single Mother w/ children	13	12%	9	13%	22	12%
Grandparent, parent w/ children	6	6%	2	3%	8	4%
Grandparent w/ children	1	1%	2	3%	3	2%
Guardian w/ children	1	1%	1	1%	2	1%
Parent & stepparent w/ children	1	1%	0	0%	1	1%
Single Father w/ children	0	0%	0	0%	0	0%
Other	0	0%	0	0%	0	0%

Table 4: Child's Current Age

181 respondents indicated child's current age in months			
	Mean	Minimum	Maximum
Current age	45	6	84
Age when service began	24	0	60

Table 5: Age When Service Began by Current Age

111 Children began receiving services between birth and age 2			
	Mean	Minimum	Maximum
Current age	40	6	84
Age when service began	14	0	32

Table 6: Age When Services Began by Current Age

70 Children began receiving services between age 3 and 5			
	Mean	Minimum	Maximum
Current age	54	39	79
Age when service began	39	36	60

Table 7: Family Income

Family Income	# of respondents	% of 177	Grouped	% of 177 by group	
Under \$10,500	17	10%	43	24%	Low
\$10,501 - \$21,000	9	5%			
\$21,001 - \$31,500	17	10%			
\$31,501 - \$42,000	15	8%	72	41%	Middle
\$42,001 - \$52,500	18	10%			
\$52,501 - \$63,000	24	14%			
\$63,001 - \$73,500	15	8%			
\$73,501 - \$84,000	20	11%	62	35%	High
\$84,001 - \$105,000	14	8%			
Over \$105,000	28	16%			

Table 8: Parent's Identified Concerns for Their Child

	# of respondents	% of total respondents (188)
Child Development (only)	60	32%
Health (only)	1	1%
Behavior (only)	7	4%
2 or more of the above	101	54%
Developmental and health concerns	11	6%
Developmental and behavioral concerns	63	34%
Health and behavioral concerns	0	0%
All three of the above	27	14%
No concerns	18	10%
Others have concerns	1	1%

Services received in the past year: Tables 10 – 13

Table 10 - Specialized Services Use by Age When Services Began and Current Age

Service	Total who used each service 0-5 (181)	% of total 0-5 (181)	Started Services between ages 0-2 (111)				Started Services between ages 3-5 (70)			ALL children 3->5 (144)				
			Total	Current Age		Total	% of 70	Current Age						
				% of 111	% of 0-2 (37)			% of 3-<5 (74)	% of 70		% of 3->5 (70)			
Speech/Language Therapy	143	79%	84	76%	19	51%	65	88%	59	84%	59	84%	124	86%
Special Education	107	59%	71	64%	22	59%	49	66%	36	51%	36	51%	85	59%
Occupational Therapy	86	48%	72	65%	22	59%	50	68%	14	20%	14	20%	64	44%
Audiological Services	60	33%	39	35%	8	22%	31	42%	21	30%	21	30%	52	36%
Physical Therapy	57	31%	54	49%	27	73%	27	36%	3	4%	3	4%	30	21%
Vision Services	38	21%	24	22%	9	24%	15	20%	14	20%	14	20%	29	20%
Specialized Equipment	26	14%	23	21%	11	30%	12	16%	3	4%	3	4%	15	10%
Psychological Services	21	12%	14	13%	3	8%	11	15%	7	10%	7	10%	18	13%
Behavioral Counseling	13	7%	7	6%	0	0%	7	9%	6	9%	6	9%	13	9%
Other	12	7%	12	11%	4	11%	8	11%	0	0%	0	0%	8	6%

Table 11 – Specialized Services Use by Income

Service	Total who used each service (177)	% of total (177)	Low Income: Under \$31,501 (43)		Mid Income: \$31,501 - \$73,500 (72)		High Income: Over \$73,500 (62)	
			Count	%	Count	%	Count	%
Speech/Language Therapy	142	80%	31	72%	56	78%	55	89%
Special Education	100	56%	26	60%	42	58%	32	52%
Occupational Therapy	82	46%	11	26%	37	51%	34	55%
Audiological Services	58	33%	15	35%	24	33%	19	31%
Physical Therapy	54	31%	10	23%	26	36%	18	29%
Vision Services	36	20%	10	23%	13	18%	13	21%
Specialized Equipment	27	15%	6	14%	11	15%	10	16%
Psychological Services	19	11%	3	7%	11	15%	5	8%
Behavioral Counseling	14	8%	3	7%	7	10%	4	6%
Other	13	7%	2	5%	8	11%	3	5%

Table 12 – Family Support Use by Age When Services Began and Current Age

Service	Total who used each service 0-5 (181)	% of total 0-5 (181)	Started Services between ages 0-2 (111)				Started Services between ages 3-5 (70)			ALL children 3->5 (144)				
			Total	Current Age		Total	% of 70	Current Age 3-5 (70)	% of 70	Total	% of 144			
				0-2 (37)	3->5 (74)							3-5 (70)		
Child Service Coordination	76	42%	64	58%	25	68%	39	53%	12	17%	12	17%	51	35%
Resource Materials	72	40%	50	45%	18	49%	32	43%	22	31%	22	31%	54	38%
Individualized Child Dev. Instruction	61	34%	46	41%	17	46%	29	39%	15	21%	15	21%	44	31%
Internet resources	45	25%	34	31%	11	30%	23	31%	11	16%	11	16%	34	24%
Social Work Services	39	22%	33	30%	12	32%	21	28%	6	9%	6	9%	27	19%
Resource Center or Library	37	20%	25	23%	6	16%	19	26%	12	17%	12	17%	31	22%
One to One Parent Support Link	35	19%	28	25%	9	24%	19	26%	7	10%	7	10%	26	18%
Parent Support Group	35	19%	30	27%	8	22%	22	30%	5	7%	5	7%	27	19%
Parent Education Class/Group	35	19%	23	21%	5	14%	18	24%	12	17%	12	17%	30	21%
Respite Care	26	14%	24	22%	6	16%	18	24%	2	3%	2	3%	20	14%
Child Care Subsidy	25	14%	21	19%	5	14%	16	22%	4	6%	4	6%	20	14%
Family Counseling	11	6%	8	7%	3	8%	5	7%	3	4%	3	4%	8	6%

Table 13: Family Support Services Use by Income

Service	Total who used each service (177)	% of total (177)	Income			High Income: Over \$73,500 (62)		
			Low Income: Under \$31,501 (43)	Mid Income: \$31,501 - \$73,500 (72)	High Income: Over \$73,500 (62)			
Child Service Coordination	72	41%	24	56%	33	46%	15	24%
Resource Materials	68	38%	13	30%	32	44%	23	37%
Individualized Child Dev. Instruction	59	33%	9	21%	30	42%	20	32%
Internet resources	42	24%	8	19%	19	26%	15	24%
Social Work Services	37	21%	19	44%	13	18%	5	8%
Resource Center or Library	36	20%	6	14%	20	28%	10	16%
One to One Parent Support Link	34	19%	5	12%	18	25%	11	18%
Parent Education Class/Group	33	19%	6	14%	15	21%	12	19%
Parent Support Group	32	18%	1	2%	18	25%	13	21%
Respite Care	27	15%	2	5%	16	22%	9	15%
Child Care Subsidy	24	14%	10	23%	7	10%	7	11%
Family Counseling	12	7%	1	2%	8	11%	3	5%
Other	2	1%	1	2%	1	1%	0	0%

Table 14: Family Support Services Use by Zip Code Region

	East (27)	% of 27	North (42)	% of 42	Raleigh (30)	% of 30	South (39)	% of 39	West (44)	% of 44
Transportation	0	0%	1	2%	2	7%	0	0%	0	0%
Inconvenient Location	1	4%	4	10%	3	10%	4	10%	2	5%
Wait	4	15%	3	7%	5	17%	4	10%	3	7%
Cost	0	0%	3	7%	2	7%	2	5%	3	7%
Respect	1	4%	0	0%	1	3%	4	10%	1	2%
Not Eligible	1	4%	2	5%	1	3%	2	5%	1	2%
Not Available	2	7%	3	7%	3	10%	1	3%	1	2%
Sibling Child Care	0	0%	3	7%	3	10%	2	5%	3	7%
Provider Contact	3	11%	3	7%	3	10%	2	5%	3	7%
Family Support	1	4%	2	5%	2	7%	1	3%	0	0%
Inconvenient Hours	1	4%	3	7%	2	7%	4	10%	0	0%

Accessing services: Tables 14 – 24

Table 14: Specialized Services, Items Reported as Most Helpful

Items that were most helpful	Respondents who used 1-2 services (74)	% of 74	Respondents who used 3-5 services (81)	% of 81	Respondents who used 6-9 services (25)	% of 25
Easy to contact	37	50%	34	42%	11	44%
Received help needed	49	66%	55	68%	18	72%
Helped quickly	26	35%	30	37%	9	36%
Providers worked together	27	36%	44	54%	16	64%
Providers helped to find other resources	26	35%	37	46%	13	52%
Convenient location	35	47%	35	43%	9	36%
Friendly & respectful	59	80%	58	72%	18	72%
Information was clear	42	57%	38	47%	16	64%
Received follow-up	22	30%	35	43%	12	48%
Insurance coverage	14	19%	32	40%	13	52%

Table 16: Difficulties Reported with Specialized Services

	Wait for services	% of total	Cost for services	% of total	Inconvenient location	% of total	Trans- portation	% of total	Difficulty contacting service providers	% of total
# of respondents who checked the difficulty for at least 1 service	39	21%	29	15%	25	13%	16	9%	14	7%
# of respondents who checked the difficulty for more than 1 service	18	10%	11	6%	10	5%	4	2%	4	2%

Table 16 continued

	Availability	% of total	Inconvenient hours	% of total	Eligibility	% of total	Child Care needed for other children	% of total	Disrespectful treatment	% of total	Lack of Family Support	% of total
# of respondents who checked the difficulty for at least 1 service	12	6%	11	6%	9	5%	10	5%	8	4%	7	4%
# of respondents who checked the difficulty for more than 1 service	4	2%	3	2%	6	3%	6	3%	0	0%	3	2%

Table 17: Specialized Services Difficulties by Income Range

Difficulty Area	Income Range						Sum
	Under \$31,500 (43)	% of 43	\$31,501 - \$73,000 (72)	% of 72	Over \$73,000 (62)	% of 62	
No difficulty	21	49%	46	64%	49	79%	116
Wait too long	7	16%	21	29%	9	15%	37
Cost	2	5%	19	26%	6	10%	27
Inconvenient location	6	14%	9	13%	8	13%	23
Transportation	8	19%	4	6%	2	3%	14
Difficult to contact providers	5	12%	5	7%	2	3%	12
Availability	3	7%	4	6%	4	6%	11
Inconvenient hours	6	14%	0	0%	3	5%	9
Child care needed for siblings	3	7%	3	4%	3	5%	9
Disrespectful treatment	1	2%	5	7%	2	3%	8
Eligibility	0	0%	5	7%	3	5%	8
Lack of family support	1	2%	5	7%	1	2%	7

Table 18 – Specialized Services Use by Zip Code Region

	East (27)	% of 27	North (42)	% of 42	Raleigh (30)	% of 30	South (39)	% of 39	West (44)	% of 44
	Transportation	2	7%	1	2%	5	17%	4	10%	4
Inconvenient Location	2	7%	5	12%	5	17%	4	10%	9	20%
Wait	8	30%	9	21%	7	23%	7	18%	7	16%
Cost	3	11%	7	17%	5	17%	10	26%	4	9%
Respect	1	4%	2	5%	3	10%	1	3%	1	2%
Not Eligible	1	4%	2	5%	2	7%	3	8%	1	2%
Not Available	2	7%	2	5%	6	20%	2	5%	0	0%
Sibling Child Care	0	0%	1	2%	3	10%	3	8%	3	7%
Provider Contact	1	4%	3	7%	3	10%	2	5%	4	9%
Family Support	1	4%	1	2%	2	7%	1	3%	2	5%
Inconvenient Hours	1	4%	2	5%	4	13%	2	5%	1	2%

Table 20: Family Support Services, Items Reported as Most Helpful

Items that were most helpful	Respondents who used 1-2 services (51)	% of 51	Respondents who used 3-5 services (64)	% of 64	Respondents who used 6-10 services (24)	% of 24
Easy to contact	21	41%	29	45%	13	54%
Received help needed	19	37%	46	72%	16	67%
Helped quickly	16	31%	27	42%	8	33%
Providers worked together	17	33%	29	45%	10	42%
Providers helped to find other resources	14	27%	32	50%	14	58%
Convenient location	21	41%	22	34%	7	29%
Friendly & respectful	28	55%	42	66%	15	63%
Information was clear	20	39%	29	45%	18	75%
Received follow-up	15	29%	26	41%	9	38%
Insurance coverage	8	16%	14	22%	6	25%

Table 22: Difficulties Reported with Family Support Services

	Wait for services	% of 188	Inconvenient location	% of 188	Difficulty contacting service providers	% of 188	Availability	% of 188	Child Care needed for other children	% of 188
# of respondents who checked the difficulty for at least 1 service	19	10%	15	8%	14	7%	11	6%	11	6%
# of respondents who checked the difficulty for more than 1 service	8	4%	7	4%	6	3%	5	3%	5	3%

Table 22 continued

	Cost for services	% of 188	Inconvenient hours	% of 188	Eligibility	% of 188	Disrespectful treatment	% of 188	Lack of Family Support	% of 188	Transportation	% of 188
# of respondents who checked the difficulty for at least 1 service	11	6%	10	5%	7	4%	7	4%	6	3%	3	2%
# of respondents who checked the difficulty for more than 1 service	2	1%	4	2%	3	2%	1	1%	3	2%	1	1%

Table 23: Family Support Services Difficulties by Income Range

Difficulty Area	Income Range				Sum
	Under \$31,500 (43)	\$31,501 - \$73,000 (72)	Over \$73,000 (62)	% of 188	
No difficulty	22	42	34	55%	98
Wait too long	5	11	2	3%	18
Inconvenient location	4	5	4	6%	13
Difficult to contact providers	4	6	2	3%	12
Child care needed for siblings	3	6	2	3%	11
Cost	2	6	2	3%	10
Availability	2	5	3	5%	10
Inconvenient hours	2	5	2	3%	9
Disrespectful treatment	3	3	1	2%	7
Eligibility	1	5	1	2%	7
Lack of family support	3	3	0	0%	6
Transportation	2	1	0	0%	3

Table 24: Family Support Services Use by Zip Code Region

	East (27)	% of 27	North (42)	% of 42	Raleigh (30)	% of 30	South (39)	% of 39	West (44)	% of 44
Transportation	0	0%	1	2%	2	7%	0	0%	0	0%
Inconvenient Location	1	4%	4	10%	3	10%	4	10%	2	5%
Wait	4	15%	3	7%	5	17%	4	10%	3	7%
Cost	0	0%	3	7%	2	7%	2	5%	3	7%
Respect	1	4%	0	0%	1	3%	4	10%	1	2%
Not Eligible	1	4%	2	5%	1	3%	2	5%	1	2%
Not Available	2	7%	3	7%	3	10%	1	3%	1	2%
Sibling Child Care	0	0%	3	7%	3	10%	2	5%	3	7%
Provider Contact	3	11%	3	7%	3	10%	2	5%	3	7%
Family Support	1	4%	2	5%	2	7%	1	3%	0	0%
Inconvenient Hours	1	4%	3	7%	2	7%	4	10%	0	0%

General experience receiving services and relationships with service providers: Table 25 - 27

Table 25: General Experience

	All respondent parents (183)							
	Always	% of 183	Often	% of 183	Sometimes	% of 183	Never	% of 183
A -talk about needs & strengths	99	54%	48	26%	29	16%	4	2%
B -talk about service options	65	36%	41	22%	64	35%	8	4%
C -talk about legal rights	44	24%	22	12%	71	39%	36	20%
D -parent choice of involvement in goal development	93	51%	39	21%	31	17%	8	4%
E -parent choice of involvement in deciding where & what agency will provide services	68	37%	42	23%	44	24%	19	10%
F -agreement with provider on type of services	99	54%	47	26%	30	16%	3	2%
G -agreement with provider on amount of services	82	45%	47	26%	41	22%	8	4%

Table 26: General Experience by Current Age 0-2

	Parents of children 0-2 (39)							
	Always	% of 39	Often	% of 39	Sometimes	% of 39	Never	% of 39
A -talk about needs & strengths	21	54%	12	31%	6	15%	0	0%
B -talk about service options	13	33%	13	33%	12	31%	1	3%
C -talk about legal rights	9	23%	4	10%	15	38%	9	23%
D -parent choice of involvement in goal development	26	67%	7	18%	4	10%	0	0%
E -parent choice of involvement in deciding where & what agency will provide services	20	51%	7	18%	11	28%	0	0%
F -agreement with provider on type of services	25	64%	10	26%	3	8%	0	0%
G -agreement with provider on amount of services	20	51%	14	36%	5	13%	0	0%

Table 27: General Experience by Current Age 3->5

	Parents of children 3-5 & >5 (143)							
	Always	% of 143	Often	% of 143	Sometimes	% of 143	Never	% of 143
A -talk about needs & strengths	78	55%	36	25%	23	16%	4	3%
B -talk about service options	52	36%	28	20%	72	50%	7	5%
C -talk about legal rights	35	24%	18	13%	56	39%	27	19%
D -parent choice of involvement in goal development	67	47%	32	22%	27	19%	8	6%
E -parent choice of involvement in deciding where & what agency will provide services	48	34%	35	24%	33	23%	19	13%
F -agreement with provider on type of services	74	52%	37	26%	27	19%	3	2%
G -agreement with provider on amount of services	62	43%	33	23%	36	25%	8	6%

APPENDIX B

Wake County SmartStart

PARENT QUESTIONNAIRE

Wake County SmartStart needs you as a partner to tell us what your child needs and what your family needs to provide the nurturing environment and specialized services that are so critical during your child's early years.

Instructions

- Everything that you report on this questionnaire will be kept completely confidential. We will not share any identifying information with any service agency or anyone outside the Wake County SmartStart Evaluation Team.
- Please address every question. If you do not understand a question, please answer it the best that you can.
- You can refuse to answer any question by drawing a line through the question.

Please answer questions according to your young child who has special needs, delays or difficulty with their development. If you have more than one child with special needs or delays, **ONLY ANSWER FOR ONE CHILD.**

Please base your answers on **CURRENT** services.

1. What is the month and year of your child's birth? _____
2. At what age did your child first begin receiving services? _____
3. Have you been told about concerns by a health or child development specialist or do you have concerns about your child's skills or health in any of the following areas: (check all that apply)
 - How your child is developing (walking, pre-writing or drawing, thinking or talking skills)
 - How healthy your child is (health)
 - How your child behaves or how well your child relates to others (behavioral, emotional, social skills)
 - There are no concerns about my child's health or skills
 - Someone else has concerns about my child's health or skills but I do not

4. We would like to know what programs or services your child has used IN THE PAST YEAR.
 → Circle Y or N for each program used
 → Check the box showing any difficulties you had trying to get service for your child.

SPECIALIZED SERVICES

For each service that you used or would like to have used, DID YOU HAVE ANY OF THE FOLLOWING DIFFICULTIES? (Put a check in each box to show your answers)

DID YOU USED THIS SERVICE?														
	Yes - used the service	No - did not use the service	No difficulties	Transportation issues	Location not convenient	Wait for service too long	Cost too much/no insurance	Not treated with respect	Not eligible	Service not available	No child care for other children	Service providers were difficult to contact	Lack of family support	Hours not convenient
A. Special education and/or developmental instruction	Y	N												
B. Physical therapy	Y	N												
C. Occupational therapy	Y	N												
D. Speech/Language therapy	Y	N												
E. Vision services	Y	N												
F. Audiological services (hearing)	Y	N												
G. Psychological services	Y	N												
H. Specialized equipment	Y	N												
I. Behavioral counseling	Y	N												
J. Other:	Y	N												

- In general, what made these services **most helpful** (check all that apply)?
- Agencies were easy to contact
 - We received the kind of help my child/family needed
 - We were helped quickly
 - Service providers worked together with other agencies
 - Service providers helped us find other resources
 - The service location was convenient
 - Service providers were friendly and respectful
 - The information they gave was clear and accurate
 - They followed up to find out how my child/family was doing
 - Service was covered by insurance
 - None of the above
 - Other _____

FAMILY SUPPORT SERVICES

For each service that you used or would like to have used, DID YOU HAVE ANY OF THE FOLLOWING DIFFICULTIES? (Put a check in the box to show your answers)

DID YOU USE THIS SERVICE?	DID YOU USE THIS SERVICE?		DIFFICULTIES?											
	Yes - used the service	No - did not use the service	No difficulties	Transportation issues	Location not convenient	Wait for service too long	Cost too much	Not treated with respect	Not eligible	Service not available	No child care for other children	Service providers were difficult to contact	Lack of family support	Hours not convenient
A. Resource materials	Y	N												
B. Resource center or library	Y	N												
C. Internet resources	Y	N												
D. Child Service Coordination	Y	N												
E. Social Work services	Y	N												
F. Respite care	Y	N												
G. One to one parent support link	Y	N												
H. Parent support group	Y	N												
I. Parent education class or workshop	Y	N												
J. Individualized child development instruction	Y	N												
K. Family counseling	Y	N												
L. Child Care Subsidy	Y	N												
M. Other:	Y	N												

→ In general, what made these services most helpful (check all that apply)?

- Agencies were easy to contact
- We received the kind of help my child/family needed
- We were helped quickly
- Service providers worked together with other agencies
- Service providers helped us find other resources
- The service location was convenient
- Service providers were friendly and respectful
- The information they gave was clear and accurate
- They followed up to find out how my child/family was doing
- Service was covered by insurance
- None of the above
- Other _____

5. Please tell us which answer best describes your general experience receiving services for your child.

	Never	Sometimes	Often	Always
A. Service providers talk with you about the needs and strengths of your child	N	S	O	A
B. Service providers talk with you about your service options	N	S	O	A
C. Service providers talk with you about your legal rights	N	S	O	A
D. You are able to choose the amount of involvement that you, as a parent have in deciding the service goals for your child and family (such as developing the IFSP, IEP or other goal plan)	N	S	O	A
E. You are able to choose the amount of involvement that you as a parent have in deciding where and from what agency your child will receive services	N	S	O	A
F. You are in agreement with service providers on the type of services your child needs	N	S	O	A
G. You are in agreement with service providers on how often your child receives services	N	S	O	A

6. What type of child care arrangements do you have for your child? (Let us know if you do not use child care. Check the **ONE** answer that is used most often. **DO NOT** include occasional babysitting)

- I do not need child care because my child is cared for in my home by a parent or grandparent
- Care in your home by someone other than a parent or grandparent (i.e. nanny)
- Care in the home of a relative or neighbor
- Care in a day care home
- Care in a child care center of your choice

7. Has your child ever been asked to leave child care or have you ever been refused care based on your child's special needs? Y N

IF YES → Due to behavioral issues? Y N
 Due to developmental or health issues? Y N

8. How important is it to you that your child receive services in either an inclusive setting (regular day care, preschool or community setting) or a self contained setting (developmental day or other program where all children in the group have special needs)
- It is **very important** that my child is served in an inclusive setting
 - Somewhat important** that my child is served in an inclusive setting
 - It does not matter** if my child is served in an inclusive setting or in a setting with other children with special needs
 - It is **somewhat important** that my child is served in a setting with other children with special needs
 - It is **very important** that my child is served in a setting with other children with special needs
 - I do not have an opinion** about inclusive or self-contained settings
9. Overall, how do you feel about services for children with special needs in Wake County?
-
-

The last 7 questions will help us group your answers with those from other families who completed this questionnaire

10. What is your zip code? _____

11. How do you identify your family's primary race (*check one, if mixed, please list under other*)?

- | | |
|---|--|
| <input type="checkbox"/> African American/black | <input type="checkbox"/> Latino/Hispanic |
| <input type="checkbox"/> Asian/Pacific Islander | <input type="checkbox"/> Caucasian/White |
| <input type="checkbox"/> Native American/Indian | <input type="checkbox"/> Other _____ |

12. Is your family Latino or Hispanic?

Y N

13. Please check the block below that best describes your household family structure (*check one*).

- | | |
|--|--|
| <input type="checkbox"/> Mother & Father with children | <input type="checkbox"/> Single Mother with children |
| <input type="checkbox"/> Grandparent with children | <input type="checkbox"/> Single Father with children |
| <input type="checkbox"/> Parent & stepparent with children | <input type="checkbox"/> Grandparent, parent with children |
| <input type="checkbox"/> Guardian with children | <input type="checkbox"/> Other _____ |

14. Counting yourself, how many people live in your household? _____

15. What is your age? _____

16. What is your role in the household?

- Mother
- Father
- Grandparent
- Guardian

- Foster Parent
- Step Parent
- Other (specify) _____

17. Please check the box that best describes the highest level of education for each parent living in your home (*Mother/Father may be used to include stepparents*):

<u>Mother</u>	<u>Father</u>	<u>Education</u>
<input type="checkbox"/>	<input type="checkbox"/>	Completed grade (Please circle - 1 2 3 4 5 6 7 8 9 10 11 12)
<input type="checkbox"/>	<input type="checkbox"/>	High School Diploma (or GED)
<input type="checkbox"/>	<input type="checkbox"/>	Associate's Degree (or 2 yr. degree)
<input type="checkbox"/>	<input type="checkbox"/>	Bachelor's Degree
<input type="checkbox"/>	<input type="checkbox"/>	Master's Degree
<input type="checkbox"/>	<input type="checkbox"/>	Ph.D. or Professional Degree

18. Is your child covered by Health Insurance? Y N

IF Yes → from what source?

- Private insurance through parent or other family member's employer
- Private insurance - independently purchased
- Medicaid
- Health Choice

IF NO → Which of the following prevent your family from getting health insurance for your child?

- Cost too much
- We are not eligible
- The wait is too long
- We need more information
- We do not need health insurance
- Other _____

We want to estimate what portion of your families' income is spent on equipment or services to address your child's needs.

19. Approximately how much do you have to pay each month for special equipment, services or medications that are specifically for your child's special needs and are **not covered** by insurance or Medicaid?

- \$0 - \$50
- \$51 - \$75
- \$76 - \$100
- \$101 - \$200
- \$201 - \$500
- Over \$500

20. Which of the following income categories best describes your household income last year before taxes (*read each category*)

- less than \$10,500
- \$10,501 to \$21,000
- \$21,001 to \$31,500
- \$31,501 to \$42,000
- \$42,001 to \$52,500
- \$52,501 to \$63,000
- \$63,001 to \$73,500
- \$73,501 to \$84,000
- \$84,001 to \$105,000
- Over \$105,000

THANK YOU!

APPENDIX C

Outline for Parent Forums

- I. Welcome and completion of surveys
- II. Identify range of special needs represented and ages of children
- III. Discussion of process of accessing services for special needs
 - a. Recognition of need for help
 - b. Identification/referral of services
 - c. Accessing services
 - d. Satisfaction with success
- IV. Discussion of Family Support
 - a. What does "family support" mean?
 - b. What types of family support have helped?
 - c. What family support have you needed and been unable to get?
- IV. Do you have the personal power to choose your level of involvement in the process?
 - a. Options for services
 - b. Amount and intensity of services
 - c. From whom you receive services
 - d. When and where you receive services
- V. What are the strengths and weaknesses of the current system as it works/does not work for your family?
 - a. What are barriers?
 - b. What has been the most helpful?
 - c. What has been the most difficult to navigate?
- VI. Wrap-up
 - a. If you had a magic wand and could change one thing about the services for children with special needs in Wake County, what would it be?
 - b. Were there any issues important to you that were NOT covered?
 - c. Thank you and appreciation for time and interest.

APPENDIX D

Situational descriptions from families attending forums:

Family 1 – They have twins, current age 2 years and 8 months. Parents noticed differences in their son very early, soon after birth, but the pediatrician was not concerned. They pushed for the pediatrician to offer help or advise with no results. They have friends who have a child with special needs who got them in touch with the DEC and Early Intervention services. He is now receiving home services through Early Intervention.

Family 2 – Son was born with Downs Syndrome. She was immediately connected with services that begin for him at age 3 weeks. He is now 3 years and 2 months old and begins attending a Developmental Preschool in October. He received Early Intervention services in Wake County until age 3.

Family 3 – Son has been diagnosed with Autism through the DEC. She is on a waiting list to receive a full evaluation from TEACCH. Her pediatrician told her not to worry “because boys just start talking later.” Eventually she began to peruse information through other sources. She was aware of TEACCH and called them where she received a packet of information about resources. She said there was a long wait and he was 2yrs and 4 months when he finally began receiving services.

Family 4 – Mother noticed her son was not talking. Family and friends said not to worry because they are a bilingual family and boys talk later. He did not have an 18-month check-up because parents didn't realize he needed to go again before age 2. At his two-year check-up, their pediatrician suggested they get an evaluation. It has been 3 months and he is on the DEC waiting list. Mother has contacted Early Intervention services but is not receiving any direct services for her son at this time. “I fear, I don't know what he has or where he falls. I want to find another child like him. I want a name for what he has but not autism. I don't want autism but I want another name”

Family 5 – This mother discovered her child's needs through a Smart Start screening that took place through his child care center. At first she didn't believe he had any problems because her family and friends kept telling her everything was ok. It took 4 months for someone to contact her about services, and then there was another wait for the evaluation. She was connected with Early Intervention services but very little services were provided until after the evaluation was complete. He has received inclusive Early Intervention services and therapies. Her son is now 4 years and 7 months old and attending a Developmental Preschool. This mother is a single parent with income under \$10,500 a year. She is a full time student and works part time as well.

Family 6 - Parents begin to notice when their son was not talking at age 15-18 months and he was not interacting with other children. They begin looking around for services, got on a list at the DEC. The evaluation showed developmental delay with autistic tendencies. Their pediatrician did not see a concern until he was age 3 and they already had the evaluation. Their son did not begin receiving services until he was 3.5 years old. He is now 4 years and 7 months and receiving therapies and developmental intervention services in an inclusive setting after parents refused WCPSS services. Parents self-pay for all service that are not covered by insurance. Their annual income in between \$84,001 and \$105,000 and they reported spending over \$500 per month on special equipment, services or medications that are not covered by insurance.

Family 7 - Both children (now ages 7 & 5) have the same developmental pattern. Met all developmental milestones as if developing faster than the norm. Then around one year they begin to regress, loosing all speech by 18 months and a host of other developmental skills over a 6-month time frame. Family moved to Wake County and had difficulty getting started with services. There are a lot of services; the difficulty is

waiting and all the forms/paperwork. It took 2 days to get information from the phone book on where to go, then 2 to 3 months to get Early Intervention. Once they received the information in the mail it took 6 months for an evaluation and three more months to set up therapies.

Family 8 - Child was 13 weeks premature and born at Duke. Family was given a road map of what to expect by the doctors at Duke. The system has worked very well and child has improved.

Family 9 - At 6 months child was trying to crawl; at 9 months still having difficulty – parent was concerned but pediatrician said to wait and see. At 12 months the pediatrician asked why parent had waited to address the child's delays. Initially received poor Early Intervention services, after filing a complaint services improved.

Family 10 - Daughter was born at 26 weeks – mom admitted denial about delays. She saw her daughter accomplishing things that they said she wouldn't do. Then at 6 months she began to slow in development. She is now labeled with Cerebral Palsy. Parent refused surgery. Parent said she was not given enough information at diagnosis.

Family 11 - Daughter was born at 24 weeks – family moved to Wake County from out of state and it took a long time to access services. Once services started they have been ok.

Family 12 - One son died at age 7 after doctors could not determine what was wrong. Now her 4-year-old son needs speech and Mother has had difficulty getting the doctor to write the order for services – he says nothing is wrong.

Family 13 – “Parents must ask questions; seek out services. I was overwhelmed.”

Family 14 - Child was given a referral for services at birth but it was a year later before she actually got the services she needed. At first family was referred to Wake County Human Services but the service provider contacted the family only once every three months. At that time she left a lot of paperwork and literature that was not helpful. The child's doctors encouraged family to wait and see.

Family 15 - Foster parents tried to find services through the phone book. They didn't know where to go. After their child was hospitalized, she began to receive more services through Early Intervention. Doctors did not want to make the diagnosis of Fetal Alcohol Syndrome. Teachers would only address the symptoms that are familiar to them, things they know about.

Family 16 – This single mother adopted two children with developmental delays. They have only been with her for two weeks. She was informed prior to the adoption that they have special needs and was given referral information at that time. She has friends who have a child with special needs who helped her get in touch with the DEC and Early Intervention services.

Family 17 – This child had a difficult birth and was in the neonatal intensive care. Parents were aware of the strong possibility of problems, and he is still in the process of being diagnosed. Initially, a nurse came to their house every 3 months and he attended the Special Infant Care Clinic every 6 months. He is now receiving Early Intervention services.

Family 18 - Daughter was diagnosed at birth with Cerebral Palsy, and Duke provided immediate referral information once they left the hospital. Transitioning to the Wake County system was difficult. Once the proper resources were located, services began but the paperwork is endless. The Developmental preschool helped them get through the process.