

Children with Developmental Disabilities:

A Community Assessment of Lee County, North Carolina

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Introduction

This community assessment has been prepared by three students assigned to work in Lee County, North Carolina, as part of the University of North Carolina, School of Nursing, Public Health Nursing clinical practicum. Specifically, two students within the group were assigned to the Stevens Center, located in Sanford, under the leadership of preceptor Roger Bailey. It was determined early in the semester that the target population for our assessment would be young children, under the age of five, with a diagnosis of a developmental disability living in Lee County.

Though the term *community* can be defined in several manners including a distinct group related to geographical boundaries, for the purposes of this assessment, *community* is to be defined as an interactive collection of individuals. More specifically *community* is “a social network of interacting individuals...concentrated in a defined territory” (Keller, Strohschein & Briske, 2008).

The term *developmental disability* must also be defined. The Centers for Disease Control and Prevention, identifies a *developmental disability* as

A diverse group of severe chronic conditions that are due to mental and/or physical impairments. People with developmental disabilities have problems with major life activities such as language, mobility, learning, self-help, and independent living.

Developmental disabilities begin anytime during development up to 22 years of age and usually last throughout a person’s lifetime. (Centers for Disease Control and Prevention [CDC], 2009)

With these definitions in mind, it is the purpose of this problem-oriented community assessment to determine the assets and needs within Lee County, North Carolina for the community of children under the age of five who have been diagnosed with a developmental disability.

Findings of Community Assessment

Statistical information was gathered at the federal, state, and local level in regards to morbidity. Surveys were also designed and sent to parents of children with developmental disabilities and childcare facilities in Lee County. Lastly, key informant interviews were conducted to gain a better working knowledge of the systems in place to serve the target community.

Published Statistical Data

Due to the lack of information regarding the morbidity of children under the age of 5, we elected to use comparable data to estimate the population of interest. According to the 2007, US Census Bureau, 6.2 % of the population of children between the ages of 5 and 15 years had been diagnosed with some type of disability (U.S. Census Bureau, 2007a). Additionally, that same year, the US Census Bureau reported that 6.8% of the same age population within North Carolina had been diagnosed with a disability (U.S. Census Bureau, 2007b). Table 1, provides a comparison of the national and state morbidity data regarding various disabilities.

Table 1.

Population Ages 5-15 with Various Types of Disabilities

	<u>United States</u>			<u>North Carolina</u>		
	Total	Male	Female	Total	Male	Female
Population	44,461,573	22,759,971	21,701,602	1,328,302	675,821	652,481
5-15 years	SD ^a +/- 43,616	SD ^a +/-26,661	SD ^a +/-28,058	SD ^a +/-6,134	SD ^a +/-4,596	SD ^a +/-5,330
With any	6.2%	7.8%	4.6%	6.8%	8.8%	4.8%
disability	SD ^a +/-0.1%	SD ^a +/-0.1%	SD ^a +/-0.1%	SD ^a +/-0.4	SD ^a +/-0.6	SD ^a +/-0.5
With	1.1%	1.2%	1.0%	1.2%	1.3%	1.0%
sensory	SD ^a +/-0.1%	SD ^a +/-0.1%	SD ^a +/-0.1%	SD ^a +/-0.2	SD ^a +/-0.3	SD ^a +/-0.2
disability						
With	1.1%	1.2%	1.0%	1.2%	1.5%	1.0%
physical	SD ^a +/-0.1%	SD ^a +/-0.1%	SD ^a +/-0.1%	SD ^a +/-0.2	SD ^a +/-0.2	SD ^a +/-0.3
disability						
With	5.1%	6.6%	3.5%	5.6%	7.4%	3.7%
mental	SD ^a +/-0.1%	SD ^a +/-0.1%	SD ^a +/-0.1%	SD ^a +/-0.3	SD ^a +/-0.5	SD ^a +/-0.4
disability						
With self-	0.9%	1.1%	0.7%	1.0%	1.2%	0.8%
care	SD ^a +/-0.1%	SD ^a +/-0.1%	SD ^a +/-0.1%	SD ^a +/-0.2	SD ^a +/-0.2	SD ^a +/-0.2
disability						

Note. Statistical data adapted from U.S. Census Bureau (U.S. Census Bureau, 2007a) (U.S. Census Bureau, 2007b)

^a = Standard deviation

According to the 2000 U.S. Census Bureau data, of the 11,051 persons living within Lee County between the ages of 5 and 20 years, 854 of these individuals had been diagnosed with a disability (U.S. Census Bureau, 2000). This total accounts for 7.7% of the population within that

age group. Once the statistical data is compared across the populations, taking into account the larger age range of the Lee County figures, it is concluded that the diagnosis of children, with a developmental disability, living in Lee County are comparable to the national and state levels.

More specific information from the North Carolina State Center for Health Statistics, Child Health and Assessment Monitoring Program (CHAMP) was gathered to specifically review information for the target population. The 2005 survey inquired as to services received by the families. As evidenced in Table 2, the report revealed that 63.1% of the respondents with a child with a diagnosis of developmental disability were currently receiving services and/or support and another 25.6% had done so in the past (North Carolina State Center for Health Statistics, 2005a). This survey revealed that 11.2% of the children with the developmental disability diagnosis were not being served at that time (North Carolina State Center for Health Statistics, 2005a).

Table 2.

North Carolina Children Receiving Services or Support for Developmental Disability

	<u>Yes, Currently</u>				<u>Yes, in the past</u>				<u>No</u>	
	Total	N	%	C.I. ^a (95%)	N	%	C.I. ^a (95%)	N	%	
Total	97	69	68.5	56.0-788	13	15.3	8.1-27.0	15	16.3	
Under age 5	13	8	63.1	31.8-863	3	25.6	7.2-60.5	2	11.2	
Ages 5-10	33	22	63.8	42.9-806	5	12.8	4.5-31.1	6	23.4	
Ages 11-13	21	15	66.6	39.7-858	2	14.0	3.0-46.5	4	19.4	
Ages 14-17	30	24	82.2	58.2-939	3	12.0	2.7-40.1	3	5.8	

(North Carolina State Center for Health Statistics, 2005a)

^a = Confidence interval

Additionally, the CHAMP survey asked who the parents rely on for support and informational resources/tools. The majority of respondents, 67.1%, rely upon the physicians for information regarding the developmental disability of their child, as shown in Table 3 (North Carolina State Center for Health Statistics, 2005b).

Table 3.

Resources for Parents Regarding Concerns about their Child’s Developmental Disability

	<u>Friends</u>				<u>Doctors</u>			<u>Internet</u>			<u>Other</u>		
	Total	N	%	CI ^a (95)	N	%	CI ^a (95)	N	%	CI ^a (95)	N	%	CI ^a (95)
Total	3,720	232	6.0	5.2-7.0	2,371	64.2	62.3-66.0	503	13.4	12.1-14.8	614	16.4	15.0-17.9
Under age 5	1,022	70	6.8	5.2-8.9	693	67.1	63.5-70.5	142	14.8	12.3-17.6	117	11.3	9.1-13.9
Ages 5-10	1,166	70	5.7	4.3-7.4	758	65.5	62.2-68.7	153	13.0	10.9-15.5	185	15.8	13.5-18.5
Ages 11-13	592	38	6.4	4.3-9.2	353	61.1	56.3-65.7	83	13.0	10.2-16.5	118	19.5	16.0-23.6
Ages 14-17	940	54	5.1	3.8-7.0	567	60.6	56.6-64.4	125	12.5	10.2-15.2	194	21.8	18.5-25.4

(North Carolina State Center for Health Statistics, 2005b)

^a = Confidence interval

In 2007, the North Carolina State Center for Health Statistics again surveyed parents, focusing on services provided and received. Regarding children over the age of three, the survey inquired about the use of Special Education Services and the use of an Individualized Education Plan (IEP) (North Carolina State Center for Health Statistics, 2007a). According to the US Department of Education, an IEP is an individualized plan of action regarding education of any child with a disability. “The IEP creates an opportunity for teachers, parents, school administrators, related services personnel, and students (when appropriate) to work together to improve educational results for children with disabilities. The IEP is the cornerstone of a quality education for each child with a disability” (U.S. Department of Education, 2007). Of the CHAMP survey respondents, Table 4 illustrates that 3.1% of parents with children between the

ages of three and five reported that an IEP was in place for their child (North Carolina State Center for Health Statistics, 2007a).

Table 4.

Children, of varying ages, receiving intervention from Special Education Services

	<u>YES</u>				<u>NO</u>			
	Total	N	%	C.I. ^a (95%)	N	%	C.I. ^a (95%)	
Total	2,278	158	7.2	5.9-8.7	2,120	92.8	91.3-94.1	
Age 3-5	271	9	3.1	1.5-6.2	262	96.9	93.8-98.5	
Age 5-10	809	45	6.3	4.4-8.9	764	93.7	91.1-95.6	
Age 11-13	442	48	10.7	7.6-14.8	394	89.3	85.2-92.4	
Age 14-17	756	56	7.9	5.6-11.0	700	92.1	89.0-94.4	

(North Carolina State Center for Health Statistics, 2007a)

^a = Confidence interval

For children under the age of three, the same question was asked, and Table 5 shows that 2.3% of the respondents reported that Early Intervention Services were being utilized for their child (North Carolina State Center for Health Statistics, 2007b).

Table 5.

Children, under the age of 3, receiving intervention from Early Intervention Services

	<u>YES</u>				<u>NO</u>			
	Total	N	%	C.I. ^a (95%)	N	%	C.I. ^a (95%)	
Total	417	10	2.3	1.1-4.9	407	97.7	95.1-98.9	
Under 3	417	10	2.3	1.1-4.9	407	97.7	95.1-98.9	

(North Carolina State Center for Health Statistics, 2007b)

^a = Confidence interval

Statistical data provided by the North Carolina Department of Health and Human Services (NCDHHS), Division of Child Development (DCD), offered comparable data to the state statistics. According to a 2003 NCDHHS-DCD Needs and Resource Assessment, Lee County was reported to have 2.98% of the population of children under the age of two, receiving Early Intervention Services (Bryant et al., 2003). Additionally, 4.98% of children between the ages of three and five were receiving Early Intervention Services during that time (Bryant et al., 2003).

The Lee County figures were corroborated by statistics gathered from an interview with the Sandhills Children’s Developmental Services Agency. According to Tracy Kiester, 3.2% of the children in Lee County from birth to the age of three have been identified as having a developmental disability or delay and are currently being served. In children between the ages of three and five, 6.0% of the children in Lee County have been identified and are currently receiving intervention services.

Surveys

In an effort to gain a more in-depth assessment of the target community, a survey for parents of children with a diagnosis of a developmental disability was designed. Additionally, another survey was prepared for the childcare facilities within the Lee County geographic area

that care for children within the age range of birth to five years. It was determined that the surveys would be sent in cooperation with the Stevens Center, as the need for the assessment was identified by their Executive Director, Roger Bailey.

Parent Surveys. The families of children with a developmental disability were surveyed in order to gain an understanding of diagnoses, support, and resources. A two-page survey was prepared (Appendix A). The Stevens Center provided a listing of 50 families in the Lee County area who have a child with a developmental disability that had previously participated in one of their programs. The families did not necessarily have a child currently within the age range of the target community; however, appropriate information regarding their experience within the geographic community was applicable. The surveys were mailed to these families with a stamped, return addressed envelope included. Additionally, we contacted Easter Seals UCP Stepping Stones Childcare Center which is an inclusive facility for children with and without disabilities. Through this facility, another 40 families were provided with hand-delivered surveys that were to be returned to the childcare center. Of those families, approximately 50% have a child, age five or under, with a disability. Of the ninety families surveyed, three were returned undeliverable and eight were completed and returned (n=8), yielding a 9% return.

The parents reported diagnoses ranging from cerebral palsy, Down syndrome, and mental disability/delay. Each of these children had been diagnosed at birth or by the age of one year. Additionally, autism was also reported as a common diagnosis, with identification occurring by age five. More than 50% of respondents (n=8) reported a deficit in self-care skills including assistance needs with eating, dressing, and bathing.

The survey asked, “Following your child’s diagnosis, which of the following resources did you find most *helpful* for assistance in locating support services?” Figure 1 indicates the respondents had depended upon friends in most instances for support in finding services.

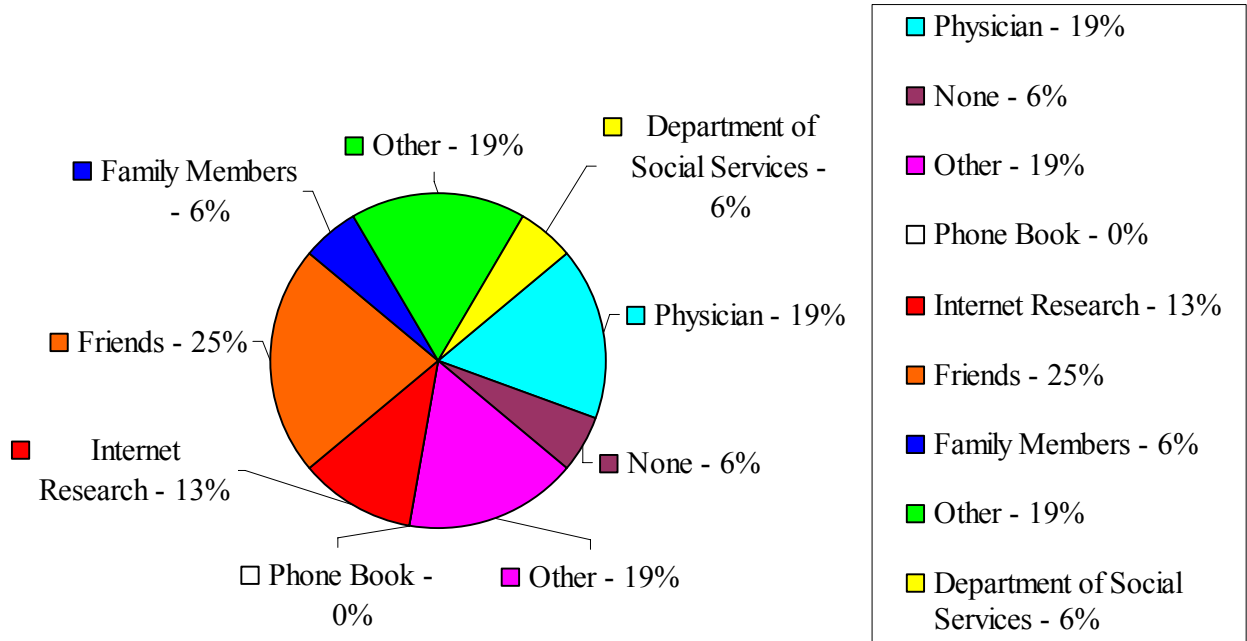


Figure 1. Who Parents Contact in Lee County When Locating Needed Resources for their Child (n=8).

The survey also asked parents, “What did you find to be the most *frustrating* aspect in locating appropriate services for your child?” Figure 2 shows that the respondents were consistent with their replies, reporting lack of information on community resources and lack of qualified childcare centers being the sources of the most frustration. Additionally, the parents reported finding frustration in locating information and parental support services.

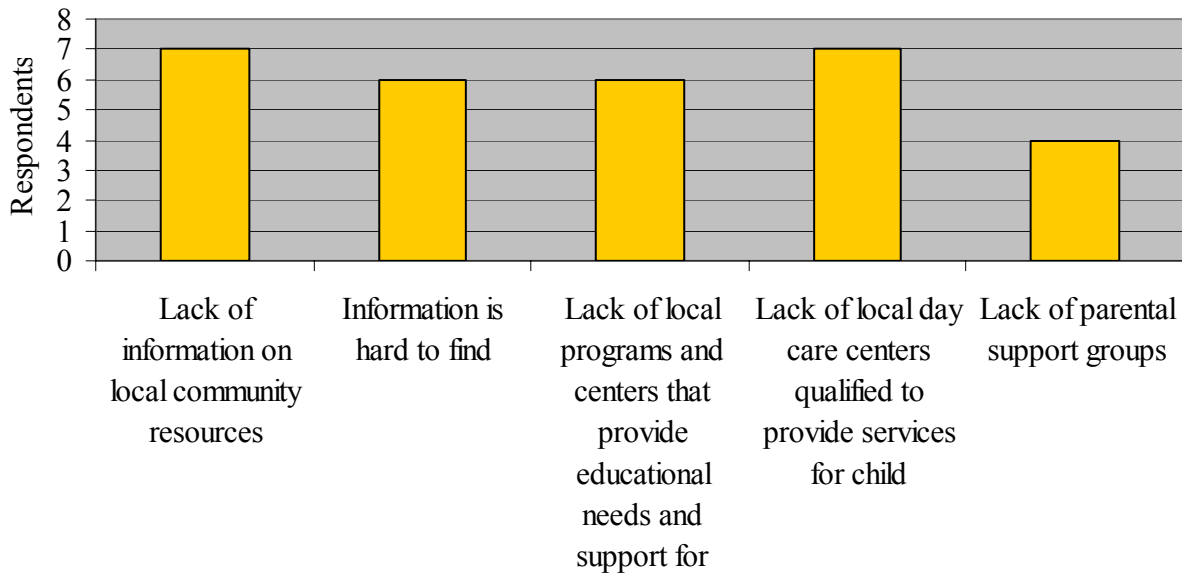


Figure 2. Frustrations Experienced by Parents in Lee County when Locating Appropriate Services for their Child (n=8).

The survey provided additional space for subjective information in regards to description of frustrations in an effort to gain a better sense of the individual experiences. One parent reported, “Finding help or someone to help is awful. Not enough support.” Another family stated that they had been unsuccessful “to get school staff and teachers to learn how to work with (their) child.” Yet another parent indicated, “Everyone just kept giving us numbers to call, no one cared.”

Another question was asked, “What services for developmental[ly] disabled children do you think are unavailable or need improvement in Lee County?” The majority of the parents (n=8) indicated a desire for assistance with respite care and inclusive programs/services for their children to attend.

Childcare Facility Surveys. Through the North Carolina Department of Health and Human Services (NCDHHS), Division of Child Development (DCD), a listing of the 75 childcare facilities within the Lee County geographic area was obtained (North Carolina Department of Health and Human Resources, 2009d). A survey was prepared for the facilities caring for the target community to assess the experience, comfort level, and competency level in providing care for this special population. The two-page survey (Appendix B) was sent to all facilities with a stamped, return addressed envelope included. Of the 75 survey sent, four were returned as undeliverable and ten were completed and returned (n=10), yielding a 14% return rate. Of note, is the fact that the only 2 inclusive childcare facilities in Lee County were among the respondents to the survey.

Of the surveys received, findings indicated that 50% of the facilities had cared for a child with a disability. This figure is most likely skewed when compared to the entire childcare facility population because people who do not care for children with a developmental disability would be less likely to respond to a survey regarding the resources and needs for the target community.

The survey asked the facilities to rank their comfort level in caring for a child with various diagnoses related to developmental disabilities. The respondents were able to classify their comfort level based upon a Likert scale with 0 being not at all comfortable, 1 being somewhat comfortable, 2 being comfortable, and 3 being very comfortable. For reporting purposes, the following results have been grouped dichotomously into Not Comfortable (Likert scores of 0-1) and Comfortable (Likert scores of 2-3). Figures 3 and 4 show the levels of comfort in caring for children with different types of developmental disabilities reported by the childcare facilities (n=10) in Lee County. Sample size variance across disability categories are the result of no response for that category from respondents.

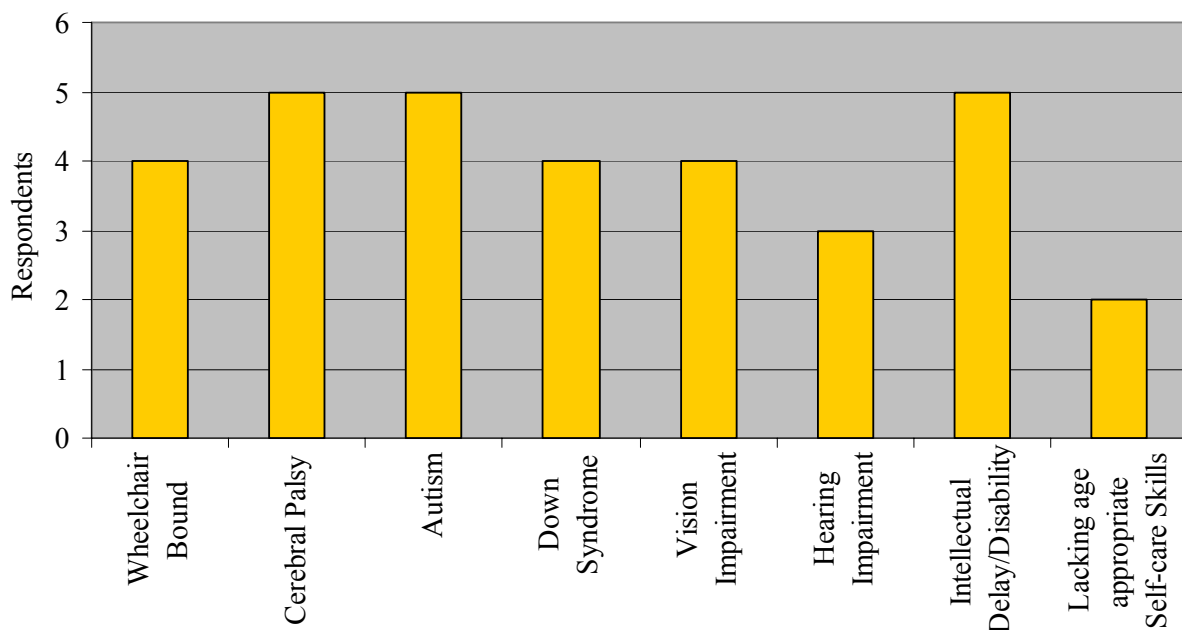


Figure 3. Childcare Centers in Lee County that are Not Comfortable in Caring for Children with Various Developmental Disabilities (n=10).

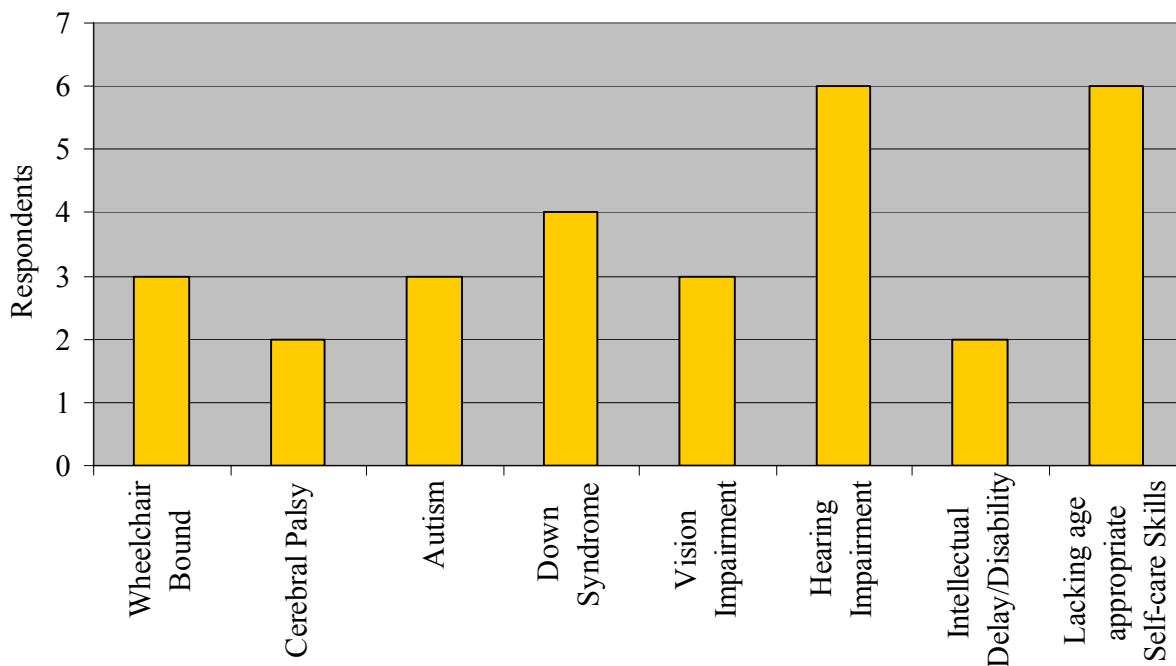


Figure 4. Childcare Centers in Lee County that are Comfortable in Caring for Children with Various Developmental Disabilities (n=10).

Recognizing that comfort in providing care for children with developmental disabilities can be influenced by competency in providing adequate care, the survey also inquired as to the competency level of the facilities in caring for a child with various diagnoses. The intention of the question was to gather information regarding the aptitude of the facilities in providing appropriate care to the target community. Using the same Likert scale and with the same application of dichotomous ranking, competent or not competent, Figures 5 and 6 demonstrate the report by the facilities in their own levels of competence in caring for children with different types of developmental disabilities. Again, sample size variance across disability categories are the result of no response for that category from respondents.

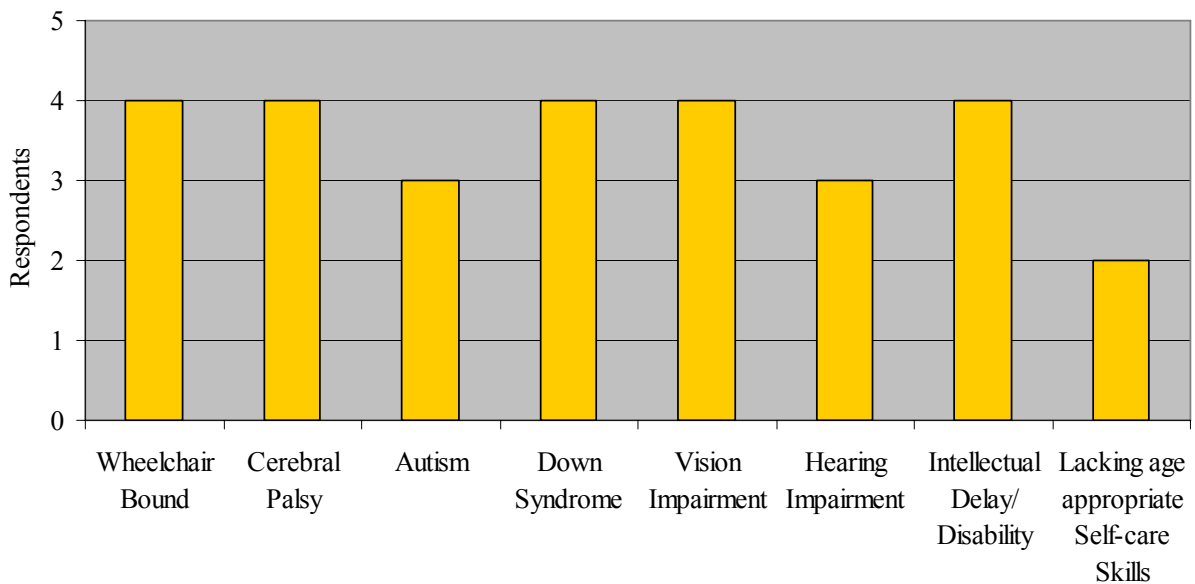


Figure 5. Childcare Centers in Lee County that Report No Competence in Caring for Children with Various Developmental Disabilities (n=10).

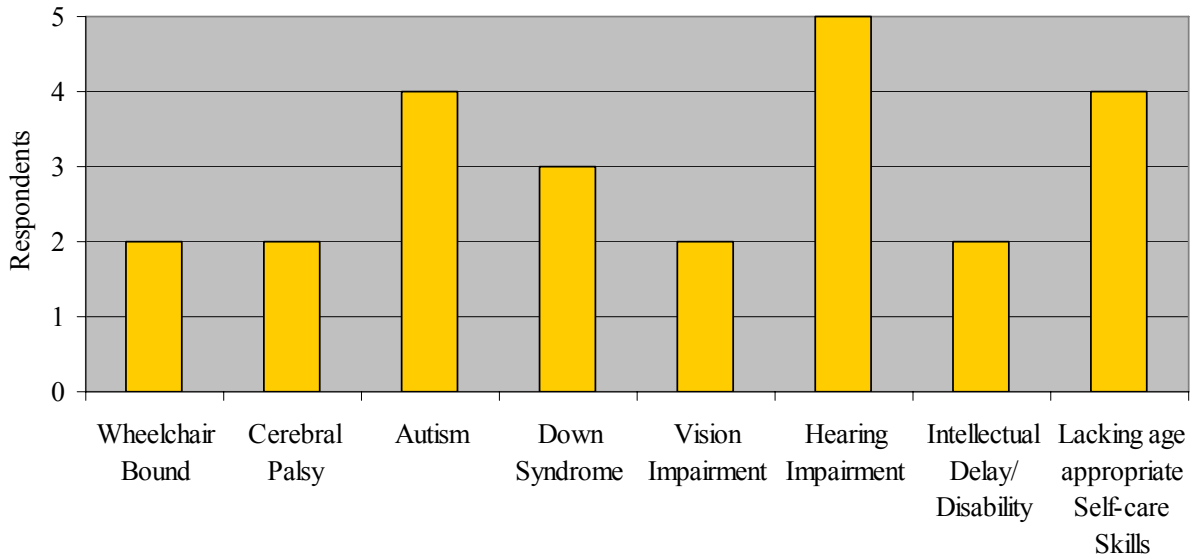


Figure 6. Childcare Centers in Lee County that Report Competence in Caring for Children with Various Developmental Disabilities (n=10).

In reviewing the data received from the surveys, it is important to note that in each category of Comfort (Figure 3) and Competence (Figure 5), two of the reporting respondents were the inclusive childcare facilities in Lee County. The results indicate that the two facilities, Lee County Schools Disabilities Preschool Program (aka: Floyd Knight Preschool) and Easter Seals UCP Stepping Stones Children’s Center, are the only facilities that report aptitude across all diagnoses. Other childcare facilities that indicated comfort or confidence in providing care were currently caring for children with specific diagnoses or had done so in the past, indicating that their experience with the developmental disability increased their ability to serve the target community.

An additional subjective question was asked of the childcare facilities, “What additional training or supports/resources do you feel would benefit your staff in servicing children with

disabilities.” This yielded answers including CPR and first aid training, improving education in working with disabled children, and information sessions related to specific diagnoses.

Key Informants

In relation to the target community, the last source for assessment information, were key informants living in Lee County. Information was gathered through face-to-face or phone interviews with representatives from Sandhills Children’s Developmental Services Agency (CDSA), Coalition for Families in Lee County , Lee County Partnership for Children, Lee County Schools Disabilities Preschool Program (aka: Floyd Knight Preschool), and Easter Seals UCP Stepping Stones Children’s Center.

Lee County Local Interagency Coordinating Council. In researching the organizations that assist with directing care for children in the disabled population, we discovered that the agencies listed above, as well as additional resource organizations have united together to form the Lee County Local Interagency Coordinating Council (Lee County LICC). This agency serves as a subset of the North Carolina Interagency Coordinating Council for Children from Birth to Five with Disabilities and Their Families which was established in 1994 as part of N.C. State Law (North Carolina General Assembly § 143B-179.5, 1994). The Lee County LICC “meets to advise and guide the North Carolina Departments of Health and Human Services and Public Instruction and other agencies regarding services for children with special needs ages birth through 5 years old” (North Carolina Department of Health and Human Resources, 2009a). Again, the Lee County LICC serves as an umbrella organization for all of the agencies in Figure 7 below. The flow chart below depicts the association of all identified assets for the target community and their areas of interest. All Lee County LICC members are not listed within the figure.

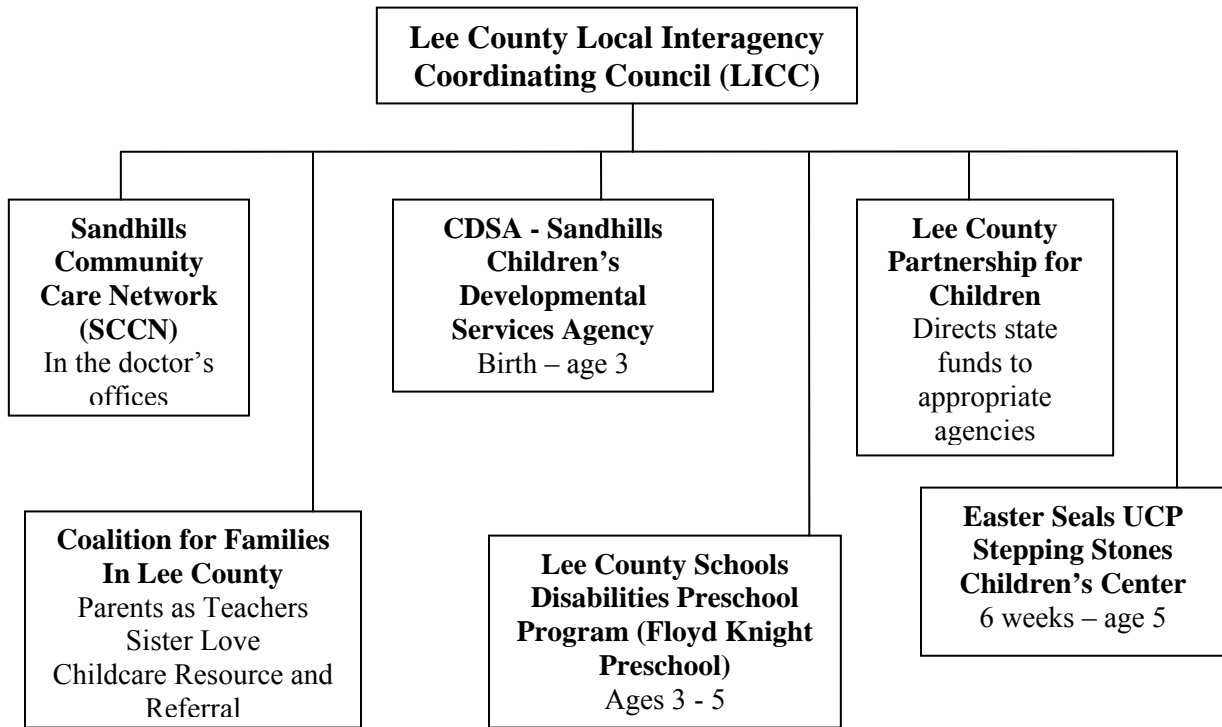


Figure 7. An overview of the key informants their affiliation with the Lee County Local Interagency Coordinating Council (LICC).

The Lee County LICC focuses on the awareness of the needs of children with disabilities throughout Lee County from the doctor’s offices to the childcare facilities, as well as incorporating parents and families on early diagnosis and intervention. Several known factors have been identified by Lee County LICC members Tracy Kiester and Karla Pomilio-Hancock. The agency attributes these as hurdles to providing adequate care to the target community. Interventions have been put into practice to try and overcome these obstacles. First, childcare facilities are hesitant to make referrals of children that have been undiagnosed and have been attending their facility. The facilities are not notifying parents due to their own lack of knowledge in accessing resources, lack of communication skills, or not feeling responsible for

acknowledging the delay of the child. Second, the lack of communication between resource facilities for children with developmental disabilities and knowledge of which facilities would be most appropriate for specific referral needs. However, the Lee County LICC has increased the communication throughout the numerous agencies which serve the target community and currently have monthly meetings to discuss how things are progressing in the geographic community. Lastly, physicians have not been willing to make early diagnoses and therefore the children and families are missing early interventions. The Lee County LICC has tried to increase awareness to providers for early intervention and knowledge of the agencies that are in the geographic community for referrals and assessments. Most recently, the Sandhills Community Care Network has been put into place to reduce the delay of early assessment and intervention.

Sandhills Community Care Network. The aforementioned Sandhills Community Care Network (SCCN) is a new program that is being utilized in Lee County. The model for this program stems from the ABCD (Assuring Better Child Health and Development) project which is a quality improvement initiative (Hay, 2004). According to Hay (2004), the program seeks to have “physician champions” within the community that can identify and then link appropriate resources for children with special needs. Currently, the SCCN model is being implemented in doctor’s offices in Lee County. They are using case managers to assist in the relay of information about concerns for children with delays from the doctor’s office to the toddler program (ages 0-2) or the preschool program (ages 3-5), depending upon the age of the child in question. The case manager is available to work with the family and guide them through the assessment process.

Lee County Partnership for Children. Lee County Partnership for Children, another Lee County LICC contributing member, is a non-profit organization that disperses funds within the geographic community that it receives from the state for Smart Start and More at Four programs

along with local donations. In an interview, employee Karla Pomilio-Hancock explained that monies are dispersed to the Coalition for Families in Lee County, Lee County Public Health Department, Lee County School System, and Easter Seals UCP Stepping Stones Children's Center in order to provide more opportunities for programs reaching the disabled population. This agency serves the children within the community that have been identified as needing intervention for school readiness and may or may not be dealing specifically with the target community related to developmental disabilities.

Coalition for Families in Lee County. The Coalition for Families is another non-profit organization that is part of the local interagency council working together to provide services for children and their families. Their community service programs include Parents as Teachers, Sister Love, and Childcare Resource and Referral. Parents as Teachers is a program working with families to assist with child development issues that parents may be unfamiliar in handling. Additionally, they attend to behavioral and social issues that may need to be addressed to assist the child with skills development. The goal of the Sister Love program is to reach populations in poverty by teaching in barbershops and other areas in the community. The program focuses on the education of young, single, black women that do not have the education or social skills to care for their children. Sister Love provides teaching on every subject that may need to be addressed and may identify some children with a developmental disability that have been missed through other screening processes. Additionally, the program assists with identifying children that would benefit from the More at Four pre-kindergarten program. Lastly, the Childcare Resource & Referral is a program that oversees the daycare providers in the Lee County geographic area. When a parent is in need of childcare, the agency is able to supply information on childcare facilities and serves to direct parents to the CDSA when needed.

Sandhills Children's Developmental Services Agency. Another agency represented in the Lee County LICC is the Sandhills Children's Developmental Services Agency (CDSA). This organization serves as the toddler intervention program within the county. The CDSA is an early intercession agency that serves children with disabilities from birth to age three and their families in Anson, Harnett, Hoke, Lee, Montgomery, Moore, Richmond, and Scotland counties. The CDSA receives referrals through word of mouth, pediatrician offices, the Health Department, and Central Carolina Community Hospital. Early identification is detected by screening in the areas of cognitive, communicative, social, emotional, and adaptive abilities. In an interview with Tracy Kiester, she explained that if a child is found to have a 30% delay in one area, a 25% delay in two areas, or have a diagnosed condition of high risk established (i.e. chromosomal genetic disorder, metabolic disorder, congenital abnormalities, fetal alcohol syndrome, <1500 grams at birth, or less than 32 weeks gestation) then they qualify for early intervention services. The services provided for the children are based on the Individualized Family Service Plan (IFSP). This document is much like the aforementioned IEP, however it centers on the specific needs of the child and family (North Carolina Department of Health and Human Resources, 2009b). The services provided could include physical therapy, occupational therapy, speech therapy, play therapy, screening for hearing and vision, assistive technology services and devices, parent training and information, psychological services, and special education. Ninety days prior to the child's third birthday they are referred to the Lee County Schools Disabilities Program, also known as Floyd Knight Preschool program, for evaluation. These children are then evaluated to determine what setting would best fit the child's learning needs: structured care, in-home care, or childcare facility setting (North Carolina Department of Health and Human Resources, 2009b).

Preschool Programs. The last interviews conducted were with representative from the only two integrative childcare facilities in the county. Both the Lee County Schools Disabilities Program, also known as Floyd Knight Preschool, and Easter Seals UCP Stepping Stones Children's Center have an inclusive 1:1 ratio of children with and without disabilities. Both facilities receive referrals from the community and are currently at full capacity.

The Lee County Schools Disabilities Preschool Program (Floyd Knight Preschool) serves 42 children ages three through five years. This organization serves as the state mandated preschool intervention program within the county. Referrals are received from the CDSA, other preschools, physicians, and the Lee County LICC agencies. The school advertises through the county school system in order to fill the typical child seats. The services are provided at no cost to the families of students with disabilities. The children must qualify for special education based on an Individual Education Plan (IEP). Director Teresa Pilson, explained that the facility is known for serving the more "severe" students, with the top two diagnoses being severe developmental delay and autism. Three instructors are present in each classroom of 14 students, with the lead teachers being birth-kindergarten certified and two assistants not requiring certification.

Easter Seals UCP Stepping Stones Children's Center is a private daycare facility currently serving 43 children ranging in ages of six weeks through five years. "The center is guided by the philosophy that children with disabilities are children first, and beyond that, they possess certain special needs that require adaptations to allow them to reach their fullest potential" (Stepping Stones Children's Center, 2008). There is a monthly childcare cost involved for each child, regardless of ability. They do accept vouchers which could prove to decrease monthly amounts. The facility remains at full capacity and due to an ever present waiting list,

they do not advertise within the community. Lindsay Tipton, Coordinator, reports that the children they serve most often are diagnosed with Down syndrome, prematurity, cerebral palsy, cleft palate, stroke, vision impairment, and medical fragility, among others. Teachers are not required to have any additional training other than that required of a five star childcare.

Community Strengths

The Individuals with Disabilities Education Act (IDEA) is a federal law that mandates provision of services for children with special needs. The IDEA Part C allows for the care of children from birth through age three. Part B dictates the care of children between the age of three and five (North Carolina Department of Health and Human Resources, 2009c). In meeting with this mandate, Lee County has established the CDSA for the supervision of children below the age of three and the Floyd Knight Preschool to serve the needs of children between the ages of three and five.

The assessment revealed that several agencies are in place to oversee the appropriate care of children with developmental disabilities once they are identified within the community. The agencies that incorporate the Lee County LICC are dedicated to the organization of services and communication among the diverse network of programs. In speaking with the key informants within the community, it became clear that there is a mutual desire to reach each and every child needing services in Lee County.

In an effort to educate the childcare providers about early identification and intervention, the Lee County LICC has created a Red Flags Meeting that provides a forum for specialist to educate childcare facilities on how to assess the children and what to do when a deficit has been noted. They are currently planning sessions where better assessment, intervention, and communication skills can be developed by the childcare providers.

The two inclusive childcare facilities, Floyd Knight Preschool and Stepping Stones, serve approximately 42 children with developmental disabilities within Lee County. These facilities are capable of providing early intervention needed for children with developmental disabilities.

Additionally, the Sandhills Community Care Network case managers have helped to increase the identification of available resources for child assessment and evaluation. Previously, parents may have been passed from one facility to another or speak with several agencies prior to receiving the help they need. The willingness of the physicians to apply network referral is crucial in early identification of children with special needs. The fear of “labeling” a child has been of great concern to physicians and parents in the past; however, with continued education and support, this program will hopefully prove to be effective at the local level.

Community Needs

Based on the assessment findings, the resources that are available for early detection and intervention with children with developmental disabilities are difficult to navigate. The assessment revealed that the current organization of agencies, though strong, is quite complex and there are several areas that tend to overlap one another. This supports the survey findings that revealed parental frustration with finding and accessing appropriate information. There is a need to make the system easier for parents to navigate in order to identify needed resources.

The assessment also revealed a definite need for more inclusive services for children with disabilities within the community. The use of inclusive programs affords the child with developmental disabilities to operate and explore a world that may otherwise not be available to them. A diagnosis of developmental disability often isolates a child and in turn the isolation can affect the psychosocial health of the child and family (Evans, 2004). By using inclusive programs and assisting the child in working within the limitations of the diagnosis, the programs

can promote self-worth and self-esteem (Evans, 2004). Through the surveys, parents reported their desire to find and participate in these programs. An interview with Lindsay Tipton at Stepping Stones revealed that they have a long waiting list that rarely rolls, therefore, the needs of children with developmental disabilities on that list and their families may not be met.

In addition to childcare facilities, the parents indicated the desire for inclusive play and sports groups. Through the scope of this assessment, this is a need for which we identified no assets within the geographic community. The programs offered by the Stevens Center currently focus on the adult population with developmental disabilities, and though they have some programs in place for children, none of the ongoing programs address the psychosocial needs of the children age five and under. For the past two summers the Stevens Center has offered a successful program titled Party, Paint and Playtime which is offered to two to four-year-old children and focuses on healthful living. It has been an inclusive program led by students from the University of North Carolina, School of Nursing (UNC-SON) and supported by the students from Central Carolina Community College (CCCC). However, according to Roger Bailey of the Stevens Center, the program is not currently scheduled to continue due to lack of availability of students.

Additionally, the educational need of childcare providers in relation to developmental disabilities must be addressed. Though the Lee County LICC conducts a Red Flags Meeting, the concern is that they may not be reaching the appropriate providers within the community. Key informants revealed their concern for lack of participation at this intervention and teaching event. The concern is that they are not adequately reaching the average childcare provider and many of the participants are attending due to facility licensing requirements for continuing education related to star ratings. Early identification and intervention with any developmental delay is

crucial (Goldfeld, Wright & Oberklaid, 2003), and much time and energy should be spent on confidently educating the care providers and allowing them to recognize and confidently raise concern when developmental milestones are not being met. At that point, the appropriate referral services can be contacted and the assessment, evaluation, and intervention process may begin.

Community Priorities

Review of the assessment has revealed numerous resource assets and needs for the target community. Table 6 outlines the Force Field Analysis surrounding the desired change for early identification and intervention with children with developmental disabilities. In reviewing the competing forces there is a need to identify ways to increase the power of the driving factors or reduce the power of the restraining factors that are constantly at work against one another (Dieckmann, 2009).

Table 6.

Force Field Analysis

Driving Forces →	← Restraining Forces
<p>Federal and State mandated agencies that overlook the care of young children</p> <p>Early identification through physicians and case managers with the SCCN</p> <p>Local agencies that are in place to oversee the services provided to children with developmental disabilities</p> <ul style="list-style-type: none"> ▪ Desire of the individuals within the local agencies to improve early identification and intervention for children in the target community ▪ Two inclusive childcare facilities currently operating in Lee County – serving approximately 42 children with diagnosed delays or disabilities 	<p>Inadequate training of childcare providers which limits their ability to identify developmental delays</p> <ul style="list-style-type: none"> ▪ Hesitancy of childcare providers to speak out when a developmental delay is suspected ▪ Hesitancy of physicians to “label” a child with an early diagnosis ▪ Hesitancy of parents to follow-up on suspected developmental delays or recommendations from physician or childcare provider – thinking that the child may <i>catch up</i> eventually <p>Minimal inclusive services in the county for the target community – which would offer an outlet for child interaction and social development</p> <ul style="list-style-type: none"> ▪ Inability of the UNC-SON students to continue the Party, Paint and Playtime inclusive program at the Stevens Center ▪ Only two childcare facilities report the highest level of competency and comfort in dealing with various developmental disabilities – one has a waitlist that rarely rolls <p>Appropriate resources are difficult for the parents to identify</p>

Note. The identified desired change is for the children in Lee County, under the age of five, to be appropriately assessed for developmental disabilities, providing early detection, and provision of early interventions. Each bullet item serves to further support the three main forces in each column.

Understanding that federal, state, and local programs are in place to appropriately identify and intervene with needed services, the agencies within the geographical community must continue to campaign for the detection of members that would qualify for the target community, in turn increasing each of the driving forces that have been identified.

The restraining forces are categorized into three main areas of concern: lack of childcare provider training, lack of availability of inclusive services, and difficult navigation of the resources for the target community. The subsets under each main category support the further restraint by each force. For example, the lack of training for the childcare provider could provide a situation in which the child may not be identified at an early stage as having a developmental disability. The provider is in a unique position, as they are able to not only view the social interactions of the child within a peer group, but also are able to readily compare developmental milestones across the peer group as compared to expectations. If the physician has not identified the delay as a concern at an annual check-up, and the parents feel as though their child will eventually *catch up* with peers, the child can easily be overlooked for early identification and intervention.

Another restraining force is the lack of inclusive services in the county for the target community. These programs would offer an outlet for child interaction and social development thereby increasing the self-worth and self-esteem of a child with a developmental disability (Evans, 2004).

Lastly, the navigation of the available resources within the community is difficult. The data gathered during the assessment revealed that there are numerous agencies that exist to identify and appropriately serve the needs of the child with a developmental disability; however, it may be difficult for a parent to know who they should contact. Information gathered during the

assessment led to lists of servicing agencies; however, no definitive list of which agency is responsible for a certain area has been located. The overlap of service areas among the various agencies also makes the system difficult to dissect. For a parent with a child that is newly identified for assessment or newly diagnosed, the resource list may prove to be overwhelming and cumbersome.

The assessment has identified four main areas for intervention: proper identification of children with developmental disabilities, lack of childcare provider training, lack of availability of inclusive services, and difficult navigation of the resources for the target community. In order to prioritize the appropriate intervention area, several factors must be weighed against each problem. For priority setting purposes the dynamic topics under consideration include: frequency of occurrence or potential occurrence within the population, years of potential life lost related to community contribution due to the morbidity of developmental disability, morbidity health costs, economic feasibility, propriety of agency, acceptance of change within the target community, resource availability, and legality (Dieckmann, 2009). The information in Table 7 reveals the rankings of the identified areas for intervention weighed against the various factors.

Table 7

Priority Setting for Areas Identified as Needs within the Target Community

Problems/Needs	Frequency in population	Years of Potential Life Lost due to Morbidity	Morbidity Health Costs	Economic Feasibility	Propriety	Acceptability by Target Community	Resource Availability	Legality	Effectiveness of intervention	Priority Ranking
Inadequate childcare provider training in identifying delays	9	2	10	5	10	10	8	10	10	74
Difficult navigation of services available	8	3	1	10	10	10	10	10	10	72
Inadequate identification of child with developmental disabilities or delays	3	2	10	5	10	10	8	10	10	68
Lack of inclusive services	9	2	3	5	10	10	7	10	10	66

Note: Each area was ranked on a scale of 1 (least) to 10 (most) (Dieckmann, 2009)

Recommendations

The need receiving the highest priority is the inadequate training of childcare providers to identify developmental disabilities and delays in children. Based upon the assessment, it is evident that much attention should be paid to this issue. Training classes or seminars regarding normal developmental trajectories and expectations should be provided for the childcare facility population. In order to promote participation in the training, the programs could be provided within the centers themselves thereby ensuring accessibility. By focusing the teaching on normal development, the childcare providers would understand their role in the promotion of community health and well-being as opposed to diagnosis and intervention. Much attention should be paid to the communication needs of the provider and support must be provided regarding the sharing of concerns with families. The childcare provider must be aware that they are merely raising suspicion for deviation from the developmental course and not indeed diagnosing the child with a developmental disability. Their intervention may appropriately begin the path for assessment and intervention.

In April 2008, the North Carolina Interagency Coordinating Council (NCICC) set forth specific priorities for professionals working with children under the age of five. The first of these objectives is for the childcare provider to be educated in “understanding typical and atypical development and learning” (North Carolina ICC Professional Education Committee, 2007). It would be through early detection that the progression of services can be alerted and needs identified. Throughout the priority document, the NCICC focuses on expectations and differences of the developmentally disabled child and how the provider must also encompass these unique needs into appropriate care practice (North Carolina ICC Professional Education Committee, 2007). It is the recommendation of this assessment that this document be provided to

the childcare facilities in order to promote responsibility and professionalism within the field. By understanding the charge before them, they may take greater interest in appropriate training for identification of developmental disabilities and delays.

Based upon the information gathered in the assessment, another recommendation that has been identified is the need for an awareness campaign of developmental milestones that children should be reaching at certain ages. The concern is that the child over the age of two will only see the physician at annual well-check appointments and delays may be missed during this time. In using the parents and family as an asset for the child, the recommendation involves including them in a proactive manner. Appropriate milestones should be discussed with the parents and documentation of these expected achievements should be provided at the well-visits. A telephone follow-up by the provider's office during the year may be appropriate in order to quickly evaluate the developmental advancement as well as to provide anticipatory guidance regarding the normal trajectory for development. This would also provide further supportive communication with the parents in discussion of normal developmental progression. If a parent is concerned about any delays, the proactive intervention by the provider's office may allow an outlet for further discussion, assessment, and support.

According to Healthy Carolinians 2010, when reviewing the adult population, "people with disabilities tend to have lower rates of physical activity and higher rates of obesity" and "report more anxiety, pain, sleeplessness, and days of depression and few days of vitality" (Healthy Carolinians, 2009). Due to the knowledge of this health concern within the adult populations, every effort should be made to begin engaging children in appropriate physical activity at a young age. Through the use of inclusive programs and playgroups, children with

developmental disabilities would be challenged to interact with peers through play, encouraging exercise and promoting self-value and self-esteem (Evans, 2004).

Due to the inability of the University of North Carolina (UNC) nursing school students to continue the Party, Paint and Playtime program at the Stevens Center, it is the recommendation of this assessment for the facility to find additional avenues for volunteers to continue the program. Central Carolina Community College (CCCC) is located near the Stevens Center and the college currently has an associate degree nursing curriculum. Though the students within the program are not required to participate in the public health practicum, as required by UNC, the student nurses at CCCC may be an appropriate outlet for program leadership. The CCCC students receive education regarding pediatric developmental milestones as well as training in working with the developmentally disabled population. This asset of potential resources should be explored as possible replacement leadership for the Party, Paint and Playtime inclusive program.

Lastly, the organization of the servicing agencies is not easily navigated. This is possibly the easiest task to attend to in regards to the needs assessment. Due to the numerous agencies that exist to serve the target community, it would be in the best interest of these agencies to make their services and responsibilities better known to the public. As previously mentioned, the efforts of each group may tend to overlap in some areas, making navigation even more difficult. It is the recommendation of this assessment that the agencies within the Lee County LICC design a document that can be provided to community members that easily identifies each member and their area of expertise. Contact names and numbers should be included on the document as well. With the numerous agency resources available and their strong internal organization, this should

prove to be an easily achieved task that will better serve the families of children with developmental disabilities.

Conclusion

In conclusion, the assessment of the assets surrounding the target community appears to provide a strong foundation for service. There are several agencies in place that desire to serve the population once they are identified. The needs of the target community have been recognized as weaknesses within the organizational support. If the needs are appropriately addressed, the health and well-being of the target population would increase. It should be the goal of the Lee County geographic community to appropriately identify and intervene with children under the age of five who have a developmental disability, thereby promoting the health of the community in general.

Appendix A

Parent Survey

The Stevens Center is conducting a survey of Lee County parent’s who have a child with a developmental disability. Our objectives for obtaining this information are to: 1) evaluate the services and resources available in Lee County for parents and their children with developmental disabilities 2) to begin a reference list of centers who care for developmentally disabled children, and 3) to provide resource materials and support mechanisms for parents and families of children with developmental disabilities. Your response to this survey will provide valuable information that will help us improve the quality of life of disabled children and their families.

All information provided will be kept confidential.

Survey Questions

1. How many children do you have? _____
2. How many of your children have a developmental disability? _____
3. How old is your child/children with a developmental disability? _____
4. How old was your child when he/she was diagnosed with a developmental disability? _____

5. What is the nature of your child’s disability? Please check all that apply

Wheelchair Bound _____ Cerebral Palsy _____ Autism _____
 Down Syndrome _____ Vision Impairment _____ Hearing Impairment _____
 Intellectual disability (mental retardation) _____
 Please circle the level of severity: mild moderate severe profound
 Other: Please describe _____

6. Does your child have difficulty performing age appropriate self-care skills? Yes _____ No _____
 If you check yes, please describe the specific skill(s) your child lacks

7. Following your child’s diagnosis, which of the following resources did you find most *helpful* for assistance in locating support services? Please circle all that apply.

Physician _____ Dept. of Social Services _____ School _____
 Phone Book _____ Internet Research _____ Family Members _____
 Friends _____ Other (Please indicate) _____

8. What did you find to be the most frustrating aspect in locating appropriate services for you child?

Lack of information on local community resources _____ Information is hard to find _____

Lack of local programs and centers that provide educational needs and support for parents _____

Lack of local day care centers qualified to provide services for your child _____

Lack of parental support groups _____

Other: Please describe:

9. Has your child attended a childcare facility in Lee County? *Please circle* Yes
No

10 If yes, please provide the name of the facility attended?

11. How would you rate your satisfaction in the care they provided for your child?

1	2	3	4
Extremely Dissatisfied	Somewhat Dissatisfied	Satisfied	Very satisfied

12. Please describe your reasons for being either dissatisfied or satisfied.

13. If you opt(ed) not to use a childcare program, please indicate the reasoning behind your choice.
Please check all that apply.

Family preference to have child in home _____

Lack of finances _____

Lack of adequate services located _____

Lack of confidence in providers _____

Other - *Please Explain* _____

14. What services for developmental disabled children do you think are unavailable or need improvement in Lee County? (For example inclusive after school programs, support groups etc...)

THANK YOU FOR TAKING THE TIME TO COMPLETE OUR SURVEY.

**If you would like a copy of the final report, please contact
Roger Bailey, Executive Director of the Stevens Center at 919-776-4048.**

Appendix B

Childcare Facility Survey

The Stevens Center is conducting a survey of all childcare facilities in Lee County. The information provided by your agency will assist us in evaluation of Lee County resources and needs for children with a developmental disability and help us identify ways to improve the quality of life for disabled children and their families. **All information provided will be confidential.**

Survey Questions

1. Has your facility ever served a child with a developmental disability? Yes____ No____

2. If yes, how many disabled children did your facility care for at one time? _____

3. If your facility has cared for disabled children, please check the types below. Please check all that apply.

Wheelchair Bound _____ Cerebral Palsy _____ Autism _____

Down Syndrome _____ Vision Impairment _____ Hearing Impairment _____

Intellectual disability (mental retardation) _____

Please circle the level of severity: mild moderate severe profound

Other *please describe*: _____

4. What type of age appropriate self-care assistance did the child need?

5. How would you rate your staff's comfort level in caring for a child with a diagnosis of:

	0 Not at all comfortable	1 Somewhat comfortable	2 Comfortable	3 Very Comfortable
Wheelchair Bound	0	1	2	3
Cerebral Palsy	0	1	2	3
Autism	0	1	2	3
Down Syndrome	0	1	2	3
Vision Impairment	0	1	2	3
Hearing Impairment	0	1	2	3
(mental retardation)	0	1	2	3
Lacking age appropriate self-care skills	0	1	2	3

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