

People with Disabilities in
Johnston County, North Carolina

An Action-Oriented Community Diagnosis:
Findings and Next Steps of Action

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Executive Summary

During the 2004-2005 academic year, a team of six University of North Carolina-Chapel Hill School of Public Health graduate students conducted an Action-Oriented Community Diagnosis (AOCD) in Johnston County, North Carolina to learn more about what life is like there for people with disabilities. The students were guided by two field preceptors, who served as their liaisons to this community.

The goal of an AOCD is to gather, analyze, and summarize the perspectives of community members and service providers in a community to create a complete vision of the community's strengths, challenges, and existing resources. The AOCD process is designed to culminate in a community forum where all community stakeholders come together to create action steps to work towards change.

The purpose of this document is to summarize the AOCD process, present findings, and suggest future action steps to improve life for people with disabilities in Johnston County. The AOCD process began with an overview of secondary data, which provided the team with a context of what life is like for people with disabilities living in Johnston County. The team also attended community meetings and events to gain a better understanding of disability issues in general and specifically in the county. Next, the team conducted 32 interviews and two focus groups with people in Johnston County, including community members with disabilities, family members of people with disabilities and service providers. The team then analyzed the interviews to identify themes that emerged frequently.

The next step was to plan a community forum in which the team could share the findings from their interviews and focus groups with the Johnston County community. A Community Advisory Board (CAB) was formed to help plan the forum. The CAB prioritized six themes from

the 18 that had emerged from the data. Approximately 100 Johnston County residents and other supporters attended the community forum held on April 28, 2005 in Smithfield. At the forum, the team presented an overview of the AOCD process and their findings on the six prioritized themes of transportation, schools, support for families, housing, awareness of services and knowledge of services. Next, forum attendees broke into discussion groups and came up with action steps around these themes. Afterwards, the group reassembled to share action steps and discuss their vision for the future in Johnston County for people with disabilities and their families.

At the community forum, the great potential for change in Johnston County was apparent in the number of participants, their energy and the ideas and action steps they generated. Based on these action steps, the interviews, and observations, the team makes the following recommendations for the future:

- Continue to recognize the need to combine resources and work together in order to effect change; the team supports the suggestion of a community member that a forum become an annual event in the county.
- Continue to cooperate and share resources among service providers, family members and community members with disabilities in Johnston County.
- Develop a central location where community members can learn more about services and resources available in the county; Make a comprehensive list of resources and services for people with disabilities available at this center.
- Train and educate parents about available services and disability rights.
- Consider the needs of people with disabilities (housing, schools, recreation, and employment) in future planning efforts and county development.
- Create a plan to address the transportation needs of all residents.
- Continue to invest in the establishment and growth of The Arc of Johnston County, NC as they work to empower and improve the lives of children and adults with disabilities.

The subcommittees of The Arc can be a valuable resource for future organizing efforts in the county.

- Develop a program in which key community members shadow people with disabilities to increase awareness and understanding.
- Build a village, an assisted living community in which adults with disabilities are able to live independently from their parents and pursue their goals in a supported environment.

This document was written to serve as a resource to the people of Johnston County. The paper is divided into the following sections: secondary data, findings from the interviews and team observations, community forum, methodology, and conclusion and recommendations for the future. The team intends for this document to contribute to the work currently taking place in Johnston County around the issues facing people with disabilities and their families. The AOCD team further hopes that the action steps and energy generated during this project will build upon and enhance existing efforts in the community.

Introduction to the Project

In the fall of 2004, a team of six University of North Carolina-Chapel Hill School of Public Health graduate students entered Johnston County, North Carolina to learn more about what life is like for people with disabilities. The team was guided during this process by two field advisors, Lawrence Shockey, a service provider for NC Center for the Deaf and Hard of Hearing and the parent of a child with disabilities in Johnston County, and Rene Cummins, Director of the Alliance of Disability Advocates. The purpose of the team's Action-Oriented Community Diagnosis (AOCD) was to gain a better understanding of the cultural, social, economic, and health experiences of people with disabilities and their families. The AOCD process allowed the team to come into the community with open minds and a desire to learn, rather than with a predetermined agenda and a presumption to fix problems. By soliciting, recording, and analyzing multiple perspectives, including the perspective of the team, and looking at the similarities and differences between these views, a more holistic understanding of what life is like for people with disabilities in Johnston County was developed.

In order to accomplish this, the team sought information from a variety of sources. Gaining entrée was a continual process throughout the AOCD, whereby the team made themselves known to the community and conducted observations of environmental and social factors operating within the community. The team's observations were supplemented by consulting secondary sources of data to support or refute the initial impressions and to guide the primary data collection process. Finally, the team conducted key informant interviews and focus group interviews in order to obtain multiple perspectives on the community in general and more specifically on issues facing people with disabilities and their families. Further details about how the team collected and analyzed data are provided in the methodology overview (Section IV).

For the purposes of this project, the team's definition of disability was guided by the Americans with Disabilities Act of 1990, which defines a disability as a physical or mental impairment that substantially limits one or more major life activities. Given that Johnston County is a large area and the term disability encompasses many different conditions, it was apparent from the beginning that the team would need to narrow the focus of the project in order to accomplish their goals. As the team began to form relationships within Johnston County, it became clear that the people concerned with disability issues came from a variety of different geographic areas in the county, so restricting the geographic region of the project was not the best approach. The common element that emerged was that many people were working with or were family members of people with disabilities. In particular, there was a great deal of community organizing already happening for persons with cognitive disabilities. Therefore, the team defined the population to include people with disabilities (the majority of whom have cognitive disabilities) and their families.

The team hoped to gain the perspectives of both insiders and outsiders of Johnston County in this AOCD process. Originally, the team planned to acquire the insider's perspective by interviewing community members with disabilities and their families, and the outsider's perspective by examining secondary data sources, recording their own observations of Johnston County and by interviewing people that provide services for people with disabilities, referred to as "service providers" in this document. However, the team found a great deal of overlap in these roles, as family members and people with disabilities in Johnston County were also service providers. Therefore, the outsider's perspective was limited to the team's observations of life in Johnston County and secondary data, and multiple insiders' perspectives included community members with disabilities, family members of people with disabilities and service providers.

The first section of this document summarizes the secondary data acquired through a number of sources to provide the team with a context of what life is like for people with disabilities living in Johnston County. The major findings from the interviews, focus groups and team observations are presented in Section II of this document. Section III describes the community forum. The methodology used throughout the AOCD process is described in detail in Section IV, and Section V presents the conclusion and recommendations for the future.

Section I: Secondary Data History and Demographic Profile

Johnston County was formed in 1746 and was named for Gabriel Johnston, the royal governor of North Carolina from 1734 to 1752.¹ Johnston County is located in the central part of North Carolina, bordering Wake County to the northwest and Wayne and Sampson counties to the south and east (see Appendix A for maps). The county is 792 square miles and is home to ten towns, listed in order of size: Smithfield, Clayton, Selma, Benson, Kenly, Four Oaks, Pine Level, Princeton, Wilson's Mills, and Micro.¹ Smithfield is located in the center of Johnston County, and has been the county seat since 1771; therefore, many local government agencies and services are located in Smithfield. Clayton is located between Smithfield and Raleigh, approximately 10 miles from each city. In large part because of its proximity to Wake County and Raleigh in particular, Clayton and the western part of the county has experienced tremendous growth and development in recent years, while the southeastern part of Johnston County has maintained its rural, agricultural characteristics.

According to the North Carolina Department of Commerce, as of July 2004 the population of Johnston County was 140,719.⁵ The county has experienced a 50 percent population increase between 1990 and 2000, making it the fastest growing county in North Carolina.² According to the U.S. Census Bureau, in the year 2000, 78 percent of Johnston

County's population was White, 15.7 percent was African American, and 7.7 percent was Hispanic or Latino. The Hispanic population was the fastest growing ethnic group.³

The U.S. Census Bureau provides demographic information on people over the age of 5 living with a disability in Johnston County, with the exclusion of individuals living in institutional settings. The 2000 Census reported that 24,361 individuals, over the age of five, were living with a disability in Johnston County, which represents 22 percent of that population. Among children, between the ages of 5 and 15, 1,331 or 7 percent were living with a disability. In the adult population, between the ages of 16 and 64, 17,245 individuals or 21.6 percent of people reported living with a disability. More than 50 percent of people, over age 65, reported living with a disability.⁴

The median household income in Johnson County in 2000 was \$40,872, and in 2002 the per capita personal income was estimated at \$25,502, which is approximately \$2,000 less than the per capita personal income for the entire state of North Carolina.⁵ In Johnston County, 12.8 percent of people are living in poverty, compared to 12.3 percent in the state.⁵ According to the 2003 report, *Health and Disability in North Carolina*, 49.3 percent of persons living in a household with an annual income of less than \$15,000 reported disabilities, compared to only 15 percent of persons in households with an annual income greater than \$50,000.⁶

Employment

Johnston County is home to a handful of major corporations including Bayer, Inc., Caterpillar, Inc., and the Carolina Packers, and many small businesses and not-for-profit organizations. Johnston County also boasts a thriving agricultural industry, and ranks second in tobacco production in the United States. Private industry makes up 79.6 percent of the employment in Johnston County with manufacturing, retail, educational services, and

construction constituting the largest sectors. Jobs with the county, state, and federal government make up the remaining 20.4 percent of employment in Johnston County.⁵

At the end of 2004, Johnston County reported a 3.6 percent unemployment rate and an overall 2.0 percent employment growth rate. In 2004, there were 246 new jobs announced and 299 job losses in Johnston County.⁵ Although this employment picture is not encouraging, the situation is even more challenging for people with disabilities. Among the adult population of people with disabilities in Johnston County, the employment rate is only 56.3 percent compared to 80 percent of people without disabilities.⁷

Transportation

Johnston County has a limited public transportation system. The Johnston County Area Transit System (JCATS), coordinated by the Council on Aging, is the sole public transportation provider in the county. JCATS vans run loops that serve the general public for a fee of \$3 per trip. JCATS runs one loop in the Clayton area and one in the Smithfield/Selma area, which limits this service to the residents who live in these parts of the county. According to the 2000 U.S. Census, approximately two-thirds of Johnston County residents live in rural areas, and only one-third live in urban areas that JCATS serves with its loops.³ JCATS works with many human service agencies that serve people with disabilities in Johnston County including Mental Health, Department of Social Services, Johnston County Industries, Vocational Rehabilitation, and the Johnston County Council on Aging.

Housing

The relatively affordable housing in Johnston County has contributed to the tremendous growth in the county in recent years. The percent of home ownership among Johnston County residents is 73.4 percent, and the median value of owner-occupied housing units is \$97,329 compared to \$108,300 for North Carolina and \$156,136 for neighboring Wake County.⁵ Fifteen

percent of homeowners in Johnston County contribute 35 percent or more of their household income to mortgage payments. The growth in Johnston County is evident in the increased number of housing units constructed in recent years; 37.3 percent of all housing structures in Johnston County were built between 1990 and 2004.⁸

The economic disparities in Johnston County are observable in the housing characteristics. Approximately 23.7 percent of housing units in the county are mobile homes. Among the 26.6 percent of residents who rent in the county, over one-quarter pay 35 percent or more of their household income in rent.⁸ Johnston County offers some group homes that provide a supported environment for adults with disabilities to live independently.

Education and School

In Johnston County, most people, over age 25, have attained at least a high school degree or equivalency, and 40.5 percent have had some college education or a bachelor's degree. However, 38.6 percent of people in Johnston County, over age 25, do not have a high school diploma.⁹ Among people, ages 18 to 34, in Johnston County, only 7.6 percent of people with disabilities are enrolled in a college or graduate school, compared with 10.2 percent in the population of people without disabilities, and 6.1 percent of people with disabilities have a bachelor's degree compared with 14.2 percent of people without disabilities.⁷

The Johnston County school system is the fastest growing school district in North Carolina, with approximately 1,000 new students enrolling each year.¹⁰ The Johnston County Schools' student population is now 26,418 and is expected to reach 34,418 by 2010.¹¹ The school system currently consists of 5 high schools, 9 middle schools, 17 elementary schools, 2 schools with grades K-8, and 2 schools with grades K-12.¹² Approximately 7 percent of school-aged children (ages 5 to 15) are living with a disability, of which 80 percent are living with a mental disability.¹³ The number of students with disabilities is predicted to grow as families of

children with chronic illnesses move to Johnston County for the “affordable housing within driving distance of the specialty children’s hospitals at Duke and the University of North Carolina at Chapel Hill.”¹⁴, p.1

The growth of Johnston County Schools has put a strain on resources, as schools report needed funds for additional school nurses, increased transportation, and for their Exceptional Children’s Program.^{14, 15} School nurses are important for meeting the medical needs of students with disabilities. Transportation is an issue, because the state does not provide funding for buses based on the growth in the county. According to Johnston County Schools Superintendent, the state under-funds school transportation operations by approximately \$500,000 a year.¹¹ The Exceptional Children’s Program serves students with disabilities in the county, and has been moving toward an inclusion model to integrate students with disabilities into regular classrooms.

Johnston County is attempting to address the transition needs of its students with disabilities. Five years ago, the school system began the Occupational Course of Study (OCS), a program for students who have a disability that may prevent them from graduating from high school. The program is designed to give students with disabilities the opportunity to develop independent living and employment skills to prepare them to live and work after graduating from high school.¹⁶ Currently, 200 students are enrolled in the program, and in 2004 the first class to complete the program graduated.¹⁷

Another educational program offered to people with disabilities is the Compensatory Education program at Johnston Community College. The program is designed for people with cognitive disabilities or people who have had traumatic brain injuries. The program assists people with disabilities in becoming more independent and self-directed through acquiring basic

life skills needed to function successfully in daily living.¹⁸ Johnston County does not have a four-year college, so people seeking further education must leave the county.

Health Care

Johnston Memorial Hospital, the Johnston County Health Department, Johnston County Mental Health Center and Wake Med are the primary health care facilities available for the residents of Johnston County. Johnston Memorial Hospital has been in Smithfield since 1951. Wake Med is a new facility that opened in Clayton in 2001 to meet the increasing demands for healthcare services in the northwestern part of the county. According to the NC Rural Economic Development Center, Johnston County has only 7 certified physicians per 10,000 residents compared to 23.5 per 10,000 residents in Wake County, and 92 per 10,000 residents in Orange County.¹⁹ Due to the shortage of healthcare providers, especially specialist providers, many residents of Johnston County drive to Raleigh or the hospitals at Duke University and University of North Carolina-Chapel Hill to receive medical care.

The Johnston County Health Department is located in a building adjoining the Johnston Memorial Hospital. More than half of the patients served by the Health Department are covered by Medicaid or Medicare, and 30 percent of patients have no health insurance.²⁰ In 2004, 18.4 percent of Johnston County residents were without health insurance.¹⁹ The health department has clinics for primary care, epidemiology, pediatrics, maternal health, and family planning. Federal guidelines require that patients on Medicaid must be seen within 2-3 days of calling for an appointment; however, many uninsured patients wait 1-3 months for an appointment.²⁰ For uninsured patients, a sliding scale based on income level is used to determine the fee for service. In addition to their clinical services, the health department offers the WIC nutrition program, health education programs, and environmental health services. The health department does not provide any health programs specifically for people with disabilities.²⁰

Services for People with Disabilities

Services for people with disabilities are primarily based in Smithfield, Clayton, Selma and Benson, the largest towns in Johnston County. Some services, such as physical and occupational therapy services, and home nursing, offer home-visits. Early Intervention services for pre-school children take place both in homes and at day care centers and pre-schools. Otherwise, most services are only accessible if the individual has transportation to get to the agencies providing the services. Examples include Vocational Rehabilitation, JobLink Career Center, Johnston County Industries (JCI) and Johnston County Mental Health Center (MH). In the case of JCI and MH, transportation is provided through JCATS as mentioned above.

Other services include Easter Seals-United Cerebral Palsy, Local Interagency Coordinating Council (a group of parents and service providers) and Johnston County Council on Aging. Special Olympics also has a strong presence in Johnston County, providing year-round recreational opportunities for hundreds of athletes with disabilities. Services that are based outside the county, but serve people in the county include Exceptional Children's Assistance Center and the Governor's Advocacy Council for Persons with Disabilities. Some volunteer-based groups, which have developed a presence in the county in the past few years, are First in Families of Johnston County, the Family Support Network of North Carolina, and The Arc of Johnston County, which recently incorporated.

The secondary data collected by the team provides general information about Johnston County from an outsider's perspective. During the process of gathering information, the team identified areas that would need to be supplemented with primary data from interviews and focus groups with the residents of Johnston County. In addition to asking participants about the topics in Section I, the team also asked questions about what life was like in Johnston County, and what the strengths and challenges were for people with disabilities in Johnston County. These

additional questions contributed to the team's insights about life in the county. The team also asked service providers questions related to the Americans with Disabilities Act (ADA), specifically whether their organization had an ADA coordinator (see Appendix F for the interview guides). The following section expands on the secondary data presented above with the information gathered from interviews, focus groups and team observations in the community.

Section II: Findings

The major findings from the 32 interviews, two focus groups, and the team's observations are presented below (see Appendix B-3 for a list of interviews by type). The overarching strengths and challenges for people with disabilities and their families in Johnston County are presented first. Following the overview section is a detailed explanation of each of six themes prioritized as the most important and most changeable in Johnston County (see Section IV for a description of how the team found the themes). The themes chosen are related to: Transportation, Schools, Support for Families, Housing, Community Awareness, and Knowledge of Services (a complete list of themes is found in Appendix B-1, and a table showing the frequencies with which interviewees mentioned topics is found in Appendix B-2). For each theme, the perspectives of community members with disabilities, family members of people with disabilities, service providers, and the team observations are presented. A comparison or summary statement of the different perspectives concludes each section.

Overarching Strengths

Community members with disabilities, family members and service providers expressed feelings of optimism about positive change for people with disabilities and their families in Johnston County. In particular, community members foresee great potential to mobilize resources and awareness with the recent formation of The Arc of Johnston County, NC. The Arc

“is committed to working on behalf of children and adults with disabilities to empower and improve their quality of life through advocacy, support, and education.”²¹

Community members with disabilities, family members and service providers consistently mentioned the slower-paced, rural nature as one of the best things about living in Johnston County. As described by a service provider, “Johnston County is a very beautiful county...and it's not crowded. Whether you're disabled or not disabled you really appreciate that.” According to a community member, Johnston County “is quiet, it’s peaceful. I can’t think of any other place where it’s the same.” The feeling that the residents of Johnston County are friendly and typically come together and help each other in times of need recurred throughout the interviews. A family member feels, “that is one good thing about Johnston County—the community. If there [are] people that need help, they come out.”

The importance of the Special Olympics program for people with disabilities in Johnston County was also emphasized by residents of Johnston County. Community members described the program as a source of support, recreation and social interaction for people with disabilities, and family members expressed that “it gives [their children] something to look forward to.” Another family member described Special Olympics as “a family support group. And probably, in my opinion, the only family support group in Johnston County. And it is because we all come together for our kids.”

Overarching Challenges

The shortage of state, federal, and county funding for services for people with disabilities was a challenge mentioned frequently by both service providers and community members in Johnston County. A service provider stated concisely, “there is just not enough money in the system in North Carolina.” This funding shortage results in long waitlists and limited insurance

coverage for disability-related care. The recent growth in the county has exacerbated this situation by contributing to the demand for services in the county.

Interviewees described the large, rural nature of Johnston County as a challenge to the delivery of services and knowledge of services by community members with disabilities and their families. Since most services are available in the larger towns of Clayton and Smithfield, many families in rural areas or small towns drive a long distance to receive services. Community members and service providers mentioned the lack of specialty medical services in Johnston County as a challenge, which forces residents to travel outside of the county to access these services. Service providers and community members agreed that specialized medical care, physical therapy, occupational therapy, and speech therapy can significantly improve the quality of life for people with disabilities; however, “a lot of families still have to drive to Raleigh to receive services that they need. We are lucky to be located so close to UNC and Duke which are excellent medical facilities.” However, residents of Johnston County with limited financial resources or access to transportation may not be able to take advantage of these facilities.

The team members observed another challenge in the service providers’ responses to the question of whether their organization had an ADA coordinator. Although some organizations were not required to have a coordinator, there appeared to be a general lack of awareness among service providers of the need for such a position.

Service Providers also remarked on the difficulty they face in serving the growing Latino community in Johnston County. The language barrier is a challenge to service provision as “there are just not a lot of providers who speak Spanish.” Service providers talked about cultural barriers, specifically the Latino population’s reluctance to seek out services for people with disabilities and cultural differences in how they perceive people with disabilities. The student

team also faced challenges with this population; they were unable to interview any community members with disabilities or family members of people with disabilities from the Latino population in Johnston County.

Transportation

There is a critical need for better public transportation options for people living with disabilities in Johnston County.

Community Member Perspective

“I used to go [to JCC]. I liked it. I liked learning a lot. I can’t get there anymore. I loved it, I loved my teachers...I’m trying to get back there. They have no funding, that’s the reason why we’re trying to help get money up for JCATS so we can get back on.”

Lack of transportation was the biggest challenge identified by community members living with disabilities in Johnston County. There is no public transportation system that covers the entire county, so many community members are either disconnected from services and recreational opportunities, or dependent on family members and friends to drive them to school, work, appointments, and all other activities. Many community members who attended the Comprehensive Education program at JCC used to get transported by JCATS, but the contract between JCC and JCATS was recently terminated due to funding cuts. According to one community member, “the other day one of JCATS buses was dropping kids off here and I said, is there any way I can get back on her van and she said I dunno because JCC isn’t part of JCATS anymore. I’m trying to do everything and anything to either go back to work, or go back to school.” Reliable, affordable transportation is also an important factor that enables community members to maintain a level of independence: “without [transportation] I’m going to have to – I’m already thinking of moving back in with my mom.” Another community member stated, “I think they need more transportation, other than JCATS...maybe a lot cheaper.”

Family Member Perspective

“Of course we’re concerned now with transportation, because we live in a rural area. JCATS who was the only transportation that was coming to get these [kids] with disabilities and taking them to Johnston Community College.... When I was at work, I felt good knowing that [my child] was benefiting from a wonderful program. Now he sits at home...it’s all funding.”

Family members are concerned about the lack of public transportation and the recent termination of JCATS transportation to JCC because of funding cuts. They identified this as both disrupting the routine of their children, which was identified as very important for someone with disabilities, and creating another source of stress for family members who either have to find alternative transportation, or who end up “running a taxi service” to get their children to school, work, health care appointments, and other activities. Many families report watching the JCATS van drive by their houses every day, but their children can not ride because JCATS is no longer serving JCC. In some cases, JCATS can still come to pick up their child and take them to work (for a fee), but the pick-up schedule does not make this feasible:

because the JCATS bus drove right by my house every morning, I said is there a way we can arrange transportation from our house to [where my child works]? Well, yes ma’am, you can use it, but you’ll have to get him there at 8:30 in the morning. Well I can get him there at 8:30 in the morning. He didn’t start work till noon...I can’t leave a learning disabled person for three and a half hours sitting [downtown].

Service Provider Perspective

“Well I think it is across the board a barrier that most consumers face just to get any kind of services . . . transportation is a really big barrier for all kinds of things. It is the reason why a lot of people can’t access the health care that they need, can’t go to work, or effectively continue in an employment situation because they don’t have dependable transportation.”

Service providers were well aware of the lack of public transportation for people with disabilities, and some identified it as a barrier to accessing their services. JCATS provides transportation services on a contract basis with agencies in Johnston County. Most service providers understood the challenge of trying to provide public transportation with limited funding or subsidies to a large, rural county, and realized there are very limited options for

people with disabilities. A representative from JCATS shared the following perspective on this challenge:

We have limited funding and the fact is that we don't have a lot of general public funding. It comes through agencies. The other barrier is the distance in the county...you might have one house and might not have another for 20 miles, so that becomes an obstacle.

Team Observations

The team personally experienced and recorded observations about the large, rural nature of the county that many individuals identified as a challenge for adequate public transportation coverage. The fact that the team was able to interview so many community members in their homes during the day meant that they were not at work or school. The team experienced first hand the limited options for community members with disabilities who cannot access transportation, especially community members living in rural areas. The team also recorded comments from community members and parents who reported watching the JCATS van drive by their house every day to pick up community members who are going to other agencies (i.e. Mental Health and Vocational Rehabilitation), and wondered why they couldn't ride. When the team conducted a focus group with community members at JCC, they observed the smaller class size; many students who used to attend JCC cannot get transportation anymore.

Comparison of Perspectives

There is unanimous agreement among community members, family members, and service providers that the current public transportation system in Johnston County is sorely inadequate, and there is a critical need for better public transportation options for people with disabilities. They also agree that lack of funding is the main impediment to an adequate public transportation system.

Schools

Public schools in Johnston County are not meeting the needs of some students with disabilities.

Family Member Perspective *

“He’s entitled to reading, writing and math. He’s entitled to the school activities, entitled to participate as a senior and should be included by that school system, whether they have a disability or not.”

Most family members interviewed felt that the Johnston County Schools are not meeting the needs of students with disabilities. Although many family members stated that the schools have improved significantly in the past decade or so, most cited areas where the schools could further improve to meet the needs of students with disabilities. One family member said that some schools “are seeing the need out there, and are trying to meet the challenge.” Areas that family members felt schools could improve include more inclusion of students with disabilities in academics and activities, more training for teachers and administrators, and more education of parents about the rights and services available to students with disabilities.

In general, family members shared that although some Johnston County schools have recently made efforts to include students with disabilities in school programs, some could still do more to include students with disabilities in all aspects of school life. As one family member said, “they still don’t get to participate in a lot of stuff—especially like the proms and trips—they are not included as much.” Most family members expressed that an inclusion environment can enrich the lives of students with disabilities and typically developing students, as students learn from each other and “get to know the kids they live around, go to church with.” Still, most parents cited the need for more training of teachers and administrators to make inclusion work well in Johnston County Schools.

* The community member perspective did not provide enough data on schools, so this perspective was not included in the Schools section.

In addition to training teachers for inclusion, many family members felt that teachers need more training in general to work with students with disabilities. One family member said “a lot of people hired to work with the special needs populations are not trained.” Many family members also cited the importance of knowing the rights of students with disabilities in order to negotiate services for their children, especially during the Individualized Education Program (IEP) process. As one parent stated, “it is a tug of war to get the rights for education for your kids in Johnston County.”

Service Provider Perspective

Service providers expressed that many children are waiting to be evaluated for IEP services when entering the Johnston County Schools. One service provider stated that “the IEP process needs to start, but it’s not happening.” However, another service provider felt that once families are in IEP meetings, Johnston County Schools “will ask what the families need, and if the family says they need speech three times a week, then the school will say OK and arrange for that to happen.” This service provider also felt that Johnston County Schools and the county are becoming more “tolerant” of inclusion, but that teachers need more training “so that they can understand how to better include children [with disabilities] in their program.”

Team Observations

The student team observed the impact of the recent growth in the county on Johnston County Schools, as new schools, such as West Johnston High School, and portable classrooms have been added to accommodate the increasing number of students. In addition, the team observed efforts to connect students with disabilities with typically developing students at the Special Olympics Local Games held at Smithfield Selma Senior High School.

Comparison of Perspectives

Family members and service providers agree that Johnston County Schools are improving for students with disabilities, but that the schools can still do more to meet the unique needs of students with disabilities. Family members and service providers cited the need to provide more training for teachers on how to include students with disabilities in school programs. Family members also stated that schools should include students with disabilities more in academics and activities and that parents need more education about the rights and services available to students with disabilities in order to advocate for them.

Support for Families

Parents of people living with disabilities need more support services and support groups.

Community Member Perspective

“I want my mom to help me out with that, but it’s hard for her. She has either me, my cousin, or sister all depending on her. I want her to help me, but I understand her point of view. She’s tired a lot. She has a lot of lot of stuff to do.”

Community members with disabilities identified many ways in which their parents assist them including cooking, doing laundry, house cleaning, and providing financial assistance, transportation, and emotional support. As illustrated by the quote above, they need and appreciate help from their parents but also realize that their parents are often overextended.

Family Member Perspective

“We need a support group . . . Unless you run into them or another parent knows another parent, there is nothing formalized to get these parents together and we desperately need that—we desperately need a resource room, and support group.”

Above and beyond the normal demands of parenting, parents of people with disabilities told the team about many of the unique challenges they face on a daily basis. They spoke about the time commitments and constraints. One parent said, “it really consumes your life. Our entire life is in two-hour increments. You have two hours to get something done.” They also pointed to the financial strain caused by medical bills and specialty services and problems negotiating the

system. As one parent said, “my son has had to go without some things because we couldn’t afford it.” Stress, loss of sleep, and worry about the future were often mentioned.

Parents specifically mentioned the need for information, education, financial help, and respite. Information and education were described as especially crucial when families are facing transitions, whether they are entering the system for the first time as new parents or tackling challenges related to having an adult child with a disability. One family member said, “the biggest impact on us has been the not knowing what’s going on type of feeling, of not knowing who to contact, whether we’re choosing the right route and filling out the right paperwork etc.” Family members requested more financial help in the form of more government funding and shorter waiting lists. Parents also pointed to the need for respite so they can get a break.

Parents expressed the value of their relationships with one another. Other “people that have been through it and know what is out there” were described as an excellent source of both information and emotional support. Parents mentioned meeting one another through listserves and advocacy trainings. Disability groups such as Special Olympics, First in Families, and The Arc support families in Johnston County, but parents specifically mentioned that this informal networking is more difficult for families in rural parts of the county. According to a parent, “one of the negatives of Johnston County is that it is a rural area and it is harder to identify other parents of children with disabilities. It is hard to make those connections and feel the unity.” The idea of an organized support group was mentioned in several interviews. One parent said, “I don’t see a support network here and that’s something that’s really, really needed.”

Service Provider Perspective

“Johnston County is trying to get groups together to support people . . . I want to be a good provider, I have to see what is out there for them; I have to bring it back, lay it on the table, and see if that’s what they want to do.”

Service providers in Johnston County clearly recognized the need for support for parents. According to one provider, “a community needs to care about you. You facilitate helping people by networking so that they can get that support.” They recognized that some support is already being provided informally in the community. One provider described a situation in which volunteers came together to build a ramp for a person with a disability who needed it. They also cited organizations like First in Families and the Family Support Network as places where parents can go to address some of their needs.

On the other hand, service providers recognized that there are barriers for parents in accessing services. One provider cited lack of funding by insurance companies as an obstacle: “I feel it is a travesty that we are paying all this money for insurance coverage, and families are being denied services that they need to have their children progress to live normal lives.” There are also some services that are simply not available in Johnston County. For instance, families have to travel to Wake County for autism support groups. One service provider described the need for “more support groups, more therapy services.” Another service provider hoped that the Family Support Network in Johnston County will begin to address some of the needs, including connecting parents of people with disabilities with one another.

Team Observations

Based upon conversations with parents both during interviews and team interactions with them in more informal settings, it appears that parents with younger children see their support needs differently from parents with older children. In one meeting, a family member said that when her children were first diagnosed, she was really looking for that emotional support. Now, many years later, she has learned how to cope. She is interested in education and action – getting her questions answered and finding resources that will allow her family to move forward. In general, parents of younger children appear to still be grappling with what it means to have a

child with a disability, feeling like no one understands, and not knowing the system or how to advocate for themselves and their children.

Comparison of Perspectives

Both parents of people with disabilities and service providers agree that there is a need for more support services and support groups in Johnston County. Service providers recognized the importance of their role in providing this support. Parents consider one another as their best resources and would like to find more ways to facilitate interaction between parents of children with disabilities. Although a few service providers mentioned the Family Support Network in Johnston County, many parents did not seem to be aware of this source of support.

Housing

There is a critical need for assisted living facilities and better housing options for people living with disabilities.

Community Member Perspective

“I want to get out on my own some days, but it’s hard to find housing that isn’t too expensive.”

Many community members with disabilities who were interviewed live with either a family member, friends, or in a group home. Community members expressed a desire to live independently, but were limited by the lack of affordable housing in Johnston County.

Family Member Perspective

“Our dream would be ... a village ... And ideally, we picture this village as having its own little shops, and the kids would work in them and go to them, and they would live right there in those housing facilities and there would be foster parents in the home.”

Family members pointed out the need for more housing options for people with disabilities, including more assisted living facilities and more group homes throughout the county. They also mentioned a desire for an accessible village which would address the various needs of people with disabilities, such as transportation, employment and housing.

Family members also expressed concern over what would happen when they are no longer able to care for their children with disabilities. One parent mentioned the need for “a safety net so that every night when I go to bed I don’t have to worry.” Another parent pointed out that “we have a whole segment in this county where their parents are not going to live a lot longer. What’s going to happen to them?” These points tie into family members’ desires for more assisted living facilities or the village described in the introductory quote.

Family members also expressed concerns about limited funding for housing. One parent noted that with cut-backs in social security benefits, group homes would have trouble hiring staff qualified to meet the range of needs of people with disabilities. Another parent pointed out that paying for housing often leaves people with disabilities without money to pay for other essentials like clothing and transportation. “Every bit of money that [my child] gets through Medicaid or Social Security goes to the group home, and no money left over to buy anything.”

Service Provider Perspective

“There’s a lot of group homes, but the challenge is to make sure it is run right and the clients are well taken care of.”

Service providers mentioned the need for more group homes and other housing options with qualified staff to adequately assist the residents with disabilities. One service provider said people with disabilities do want to get out on their own, “but there’s not that stepping stone where they would have assisted living as much as they would need.” Service providers also mentioned the lack of affordable housing and compared the limited reimbursement for each person in a group home with the high costs of running the home.

Team Observations

On a driving tour of Johnston County, the team observed a variety of housing structures including large newer homes, older traditional looking homes, smaller homes in public housing

projects, some apartments, and trailer homes. Team members also saw the housing facilities of people with disabilities. Some people lived with their parents in large homes or smaller trailer homes, and others lived on their own in trailer homes or apartments. Team members witnessed the barriers some people with disabilities (particularly those with cognitive disabilities) might have to living independently, such as needing assistance with transportation and paying bills.

Comparison of Perspectives

Community members, family members and service providers agree that some change is needed in the area of housing in Johnston County, although they place emphasis on different areas. Community members expressed a need for more affordable housing and a desire to live independently. Family members emphasized the need for a variety of housing options and shared their dream of a village where people with disabilities could have all their needs met. Family members echoed community members' concerns over finances, but focused on cut-backs in allowances from federal government sources, rather than the price of housing itself. Service providers agreed with the financial concerns of the other two groups, as well as the need for more housing options. Team members observed that many people with disabilities in Johnston County did not live independently, thus supporting the community members' perspective.

Community Awareness

The community needs to be more aware of the needs and abilities of people with disabilities.

Community Member Perspective

“Go out there and meet different people, like people with disabilities. Get a chance to know them a little bit instead of judging them on how they act. Some people don't give it a chance.”

Community members expressed a concern that people without disabilities often underestimate their abilities or make assumptions without getting to know them first. A community member said, “In some cases people probably look at people with disabilities

differently than they look at a person who doesn't have a disability." Another explained, "they don't know how to talk to me. They talk to me like I'm a kid. They talk to me like I'm not there." Community members also said that a lot of employers and legislators do not know about people with disabilities and should "pay a little bit more attention to people with disabilities."

Some also suggested that sensitivity training might help improve the situation.

Family Member Perspective

"A lot of people are afraid of people with disabilities... the first thing that came out of people's mouth if they didn't have a child with disabilities was 'I don't know how to react... I have never been around a child with a disability... I brought [people with disabilities], and they sat down at the meeting, and they didn't even realize it was a [person with a disability] until after the meeting... They were so flabbergasted—they got to talk to them and said 'I can't believe that, there was nothing to worry about.'"

Family members felt that many people who serve Johnston County, such as legislators, employers, health care workers, and law enforcement are not fully aware of the needs of people with disabilities and can be uncomfortable around them. They said that "people sell [people with disabilities] short", but that people with disabilities "can be a part of society if people would just let them." Family members felt strongly that the situation could be improved through "providing education about disabilities to people in the county." They often described inclusion and mentoring programs that had been successful in other places, and they are optimistic that such awareness-raising programs could have a positive impact in the county.

Service Provider Perspective

"We need to still do a lot of work to get the needs of families with children with disabilities on the radar screen of legislators who can make policy changes."

The general need for "opening people's eyes" was repeated consistently throughout service provider interviews. Service providers said that legislators and people in control of funding need to be more aware of the needs of people with disabilities. Service providers expressed that employers' lack of awareness was a substantial barrier for people with disabilities

seeking jobs as illustrated by a service provider who said, “I think there’s preconceived notions about what they can do and what they can’t do, and that’s difficult to overcome.” Service providers serving young children said daycare providers in the county are not aware of how to care for children with disabilities.

Team Observations

“I was nervous about coming to the Special Olympics basketball practice, I hadn’t really interacted much with people with cognitive disabilities and did not know what to expect. But the athletes made me feel welcome right away. One came right up to me and reached out his hand and introduced himself... He was extremely friendly.”

As illustrated in the above quote, some team members were nervous about interacting with people with disabilities, but quickly became comfortable as they spent time with them.

While attending local meetings, team members observed people expressing the importance of “opening doors and educating the community about people with disabilities.”

Comparison of Perspectives

Community members, family members, service providers, and team members all expressed the need for increased community awareness of the needs and abilities of people with disabilities, particularly among legislators and employers. Community members, family members, and team members described experiences in which people who were unfamiliar with people with disabilities felt nervous or even afraid. They all emphasized the need for more interaction and awareness to overcome this.

Knowledge of Services

People living with disabilities and their families have limited knowledge of services, and service providers have a difficult time making consumers aware of their services.

Community Member Perspective

“The services are here, they’re in place. A lot of people are not utilizing them because they are not aware of them.”

Community members agreed that people with disabilities are not fully aware of the services available to them. As described by the quote above, this limited knowledge results in the underutilization of services by community members with disabilities, and the potential that their needs are not being met.

Family Member Perspective

“I couldn’t find any help. You had to meet one criteria or another. I didn’t even know what questions to ask...They say there’s help out there, but yet when you need it, they don’t seem to be accessible. And there are a lot of programs out there that you don’t know about.”

Family members of people with disabilities described many factors that contribute to their limited knowledge of services for people with disabilities in the county. Parents believe that some agencies are not advertising their services adequately to the community. As one parent described “a lot of the programs are. . .their best kept secret. You’ve really got to find a way to get through and find out the information.” As a result, parents are left in a position in which they have “to do all that leg-work ourselves, rather than having an agency that we could rely on.” By the time many parents find out about services, their children are longer eligible.

Another factor related to the limited knowledge of services is that “there’s not a system in place that lets everybody know what’s going on.” Many parents suggested creating a central resource agency that could provide information on the full range of services offered for people with disabilities in Johnston County. Parents expressed that this agency would also provide them with a sense of security, as they would know a place exists where they can find out about services their child may need in the future. One parent described the importance of creating this center by saying, “if there is one thing I’m going to fight for in the county is to have one central place where people can go to...and they can find out everything they need to know.”

Parents consistently reported that their knowledge of services is acquired through informal channels, such as interactions with other parents of children with disabilities. Special

Olympics was described as an opportunity for parents to share information about services for their children. One parent stated, “I wouldn’t know about any of these resources had I not gotten involved in Special Olympics.”

Service Provider Perspective

“Educating the families and the public, because there’s a lot of people out there who are not accessing mental health services or any other type of services in the community.”

Service providers described many different marketing strategies used to increase awareness of their services in the community including: distributing brochures, making presentations at businesses and agencies, participating in coalitions, creating websites, posting fliers, sending out calendars of upcoming events, and participating in outreach programs. Service providers mentioned the importance of marketing their services to the general community, but described some challenges to doing this as well. One service provider stated, “we advertise to them, but it’s not a big market because you are working with people with disabilities. You’re focusing on one group.” Service providers also commented on the importance of marketing their services to healthcare providers, schools, and social service agencies that serve people with and without disabilities, as they are important sources of referrals and are not fully aware of the services in the county. Service providers who work with young children emphasized the importance of making pediatricians aware of their services, so that children can be served starting at a young age.

Service providers suggested that the rural nature of Johnston County makes it challenging for agencies to make people living in those areas aware of their services. “It’s hard to find those isolated spots.” They remarked on the challenge of reaching out to people living in the small towns explaining that, “sometimes I feel like there’s not as much, that the rural people a lot of times get left out. Especially out of services, because they’re just not aware.”

Team Observations

During meetings and interviews, the team observed both community members and service providers finding out about services in the county for the first time. Team members also observed newly formed organizations that are in the process of developing marketing materials.

Comparison of Perspectives

Community members, family members, service providers, and team members agree that people with disabilities and their families and service agencies have limited knowledge of services available in Johnston County. Although service providers believe they actively market their services to the community and other agencies, parents felt that agencies could do more to increase awareness of services, possibly by creating a central resource agency. Therefore, service providers, community members, and team members believe it would be beneficial to find new ways of connecting service providers to each other and to people with disabilities and their families.

Section III: The Community Forum Forum Planning

The planning for the community forum began at the end of February. Given the geographical size of the county, the diversity within populations of people with disabilities, and the current energy in Johnston County around this issue, it was crucial to involve the community in planning this event. The team recruited members for a Community Advisory Board (CAB) through the interviews and focus groups conducted. From the beginning, the forum planning was intended to be a participatory process with both decision-making and tasks shared by the board and the student team. The CAB consisted of 12 members including community members with disabilities, family members of people with disabilities, service providers and members of the student team. The board was also diverse in age, gender, race, and work experience.

The CAB met five times during the two months before the forum. At the first two meetings, held March 9 and March 21, the student team explained the purpose of the project and the community forum. The board also discussed the logistics of selecting a location and a date for the event. During the third meeting held on April 4, the student team demonstrated a facilitation technique to the board and explained the importance of the small group discussions that would take place at the forum. In response to a board member's request, a reporter from the *Smithfield Herald* attended this meeting and wrote a story about the forum. At the fourth meeting on April 11, the student team presented the 18 themes that emerged from the interviews and focus groups (see Appendix B-1), and the board selected the six themes that they thought were the most important and most changeable in Johnston County. Importance was defined as whether the issue described in the theme significantly affected many people with disabilities and their families. Changeability was determined based on whether the issue lent itself to the creation of concrete action steps and whether CAB members felt they were able to address that issue. These six prioritized themes are described in Section II. The final meeting on April 18 was devoted to finalizing forum logistics. This meeting was also an opportunity for the student team to consult with the board about the most appropriate techniques to use for facilitating each individual small group discussion at the forum.

The CAB was actively involved throughout the planning process, and took responsibility for coordinating several key elements of the community forum. Board members secured funding and donations from local organizations and businesses to provide additional support for the event. They negotiated the use of the Centenary United Methodist Church for the forum and assessed its accessibility for people with disabilities. The board members helped with publicity

by creating the flyer for the forum (see Appendix C-1). Finally, the board coordinated the forum entertainment, managed the resource tables, and found a caterer to provide dinner.

Community Forum

The team's project culminated in a community forum, entitled "Living with Disabilities in Johnston County: A Working Forum," held from 6 to 9 p.m. on April 28, 2005 at the Centenary United Methodist Church in Smithfield (see Appendix C-4 for the program). The purpose of this gathering was to bring together community members, family members and service providers to celebrate the strengths of Johnston County and to work together to find ways to improve the lives of people with disabilities. Approximately 100 people attended the forum.

The event began with dinner and entertainment. Resource tables were also available to provide information and to connect service providers with community members (see Appendix C-7 for a list of those service providers). Following dinner, Lawrence Shockey introduced the team to the community and outlined the agenda for the evening. After the introduction, the team provided a brief overview of the project and described the methods used to analyze the interviews and focus groups. The team then presented the main findings, starting with the strengths of living in Johnston County for people with disabilities, followed by the six themes. The community then broke into small groups to discuss each of the themes and to generate specific, achievable action steps. Each small group discussion and the resulting actions steps are described below (see Appendix C-8 for a compiled list of the action steps).

Summary of Small Group Discussions and Action Steps

Transportation

Sixteen people, including six community members with disabilities, chose to attend the small group discussion on transportation. This discussion generated impassioned personal stories and calls for reform of the current situation. The group was presented with the theme and

decided on the following goal: To improve public transportation for people with disabilities in Johnston County. In order to do this, the group identified factors that will help them achieve this goal and factors that will be barriers to achieving this goal. The group then ranked these factors according to what they believed was most important and most changeable. The “helping” factors that the group gave priority to were developed into action steps and are listed below. Many of the barriers that the group gave priority to were exactly opposite of the helping factors and reflect the current situation in Johnston County. The following action steps were generated:

1. Compile contact information for county commissioners and legislators to distribute to members in the community who would like to contact local government officials.
2. Contact JCATS in order to collect specific information about how their administration, funding, and contract process works.
3. Contact the Department of Transportation to get the contact information for individuals that are responsible for funding allocation and administration in Johnston County.
4. Start a petition to collect signatures, and submit to local government.
5. Gather information to determine how people with disabilities in Johnston County can qualify for transportation benefits under the Elderly and Disabled Transportation Assistance Program (EDTAP).
6. Research other funding opportunities for transportation for people with disabilities.
7. Contact service agencies in Johnston County to collect data regarding the need for transportation among their clients with disabilities.

Schools

The group was comprised of 11 participants, including service providers from Johnston County Schools. The facilitator asked one of the community members to read a story related to schools, and then asked questions of the group to generate discussion about similar issues or experiences that they have had in Johnston County. The group had difficulty reaching consensus on a number of issues including the interaction between students with and without disabilities, lack of resources and funding to address the needs of students of disabilities, and the IEP process. However, they did come up with the following actions steps:

1. Advocate and challenge the legislature for more funding.
2. Train and educate parents about services available to their children.
3. Bring parents and schools together via workshops and The Arc.
4. Contact The Arc of Johnston County, NC to set up an education committee.

Support for Parents

The support for parents group was comprised of 10 participants including 5 parents. During the discussion, the group identified several things that they need as parents including more access to funding, respite, counsel and support regarding legal issues such as guardianship, a central place for communication between parents, and updated resources via the library and the internet. The group agreed that several of their concerns could be addressed by a comprehensive list of available services and resources for parents of people with disabilities in Johnston County. The goal of creating this list became the focal point of the discussion. The group identified barriers as well as factors they thought would help in achieving this goal. The helping forces included The Arc, communication between groups and individuals, newsletters, media, and the Family Support Network (FSN). Barriers included the lack of communication and the need for organizational status in order to obtain grants.

The group identified several action steps related to creating a list of services and resources:

1. Begin an informal listserv – group facilitator will e-mail a summary of the ideas generated in the discussion to all small group participants.
2. Contact the Arc about setting up a discussion board for parents on the Arc website.
3. Explore possibility for bumper stickers to facilitate communication about disability issues.
4. Attend training offered by the FSN for parents who want to become support parents.
5. Connect parents to services, resources, and each other through the FSN newsletter.

Housing

The housing small group had 10 participants, including two community members. After reading a short dialogue aloud, the facilitator asked a series of questions to generate a discussion about housing. The group came up with the following housing-related issues: Having money for housing is not enough, there need to be adequate housing options; the whole community needs to be involved with making plans for housing, not just an individual family; there needs to be a central location to access resources and services; housing needs to be designed with

transportation, employment and recreation in mind; housing must be inclusive and not isolated; and the community could be more aware of the housing needs of people with disabilities.

The group defined the following long-range goal: Design housing with the multiple needs of people with disabilities in mind (i.e. transportation, employment and recreation). Related action steps were:

1. Research planned communities to come up with examples of successful designs.
2. Conduct a community assessment to find specific housing needs of people with disabilities.
3. Learn more about Circle of Friends and Life Plans to help define the community's needs.

The group also determined a short-range goal: To help individuals with disabilities to live independently using currently available resources. Related action steps were:

1. Identify current resources from organizations like Mental Health and First in Families
2. Research possible housing models in Clayton and Raleigh.
3. Find out if there are partnering resources to help people with disabilities find roommates.
4. Run a column in a local newspaper to educate the community about the lives and needs of people with disabilities.

Community Awareness

Seven people participated in the group. The group discussed the perspectives of people with disabilities as well as the perspectives of people who are unfamiliar with disabilities. They talked about the importance of community awareness in every aspect of life for people with disabilities including every day interactions at businesses, in school, when trying to find a job or housing, and in funding for programs. All agreed that once people spent time with someone with a disability their attitudes and assumptions changed. In response, the group agreed upon the following goal: To develop a program in which key community members shadow people with disabilities to increase awareness and understanding.

The group developed the following action steps related to the shadowing program:

1. Form a steering committee for the program, and select a leader of the committee.
2. Contact key community members to participate in the program.

3. Contact a variety of county agencies that serve people with disabilities to find a diverse group of people to be shadowed.
4. Coordinate publicity to bring media attention to the program.

Knowledge of Services

This small group discussion had 8 participants including family members and service providers. The facilitator asked a group member to read a quote from a family member interview and then asked a series of questions to facilitate a discussion.

The group raised the following issues: Family members have trouble sorting through the existing resource lists and information about eligibility for services; parents would benefit from better guidance on the specific services for which their child is eligible; barriers exist between school providers and private providers, and schools do not provide adequate information on the outside services available in the county; many physicians are not aware of the services available, and do not refer families to those services; healthcare providers and schools are settings that should be targeted to increase awareness of services in Johnston County.

The following action steps were generated during this discussion:

1. Create a comprehensive list of services and resources available in Johnston County and organize the list so that parents can easily find the information that they need.
2. Develop a class at Johnston Community College to inform parents of the services available in the county and to help parents navigate the system to access the services.
3. Ask the local newspapers to write a weekly story spotlighting an agency that serves people with disabilities in Johnston County.

After the small group discussions, a community member from each group reported back to the large group on the action steps their group agreed upon. Individual community members from the small groups agreed to take personal responsibility for most action steps. To close out the evening, Linda Godwin, a Community Advisory Board member, offered her vision of the future in Johnston County for people with disabilities and their families.

Section IV: Methodology Overview

Defining Community, Gaining Entrée, and Team Observations

The purpose of the team's Action-Oriented Community Diagnosis (AOCD) in Johnston County was to gain a better understanding of the cultural, social, economic, and health experiences of people with disabilities and their families. As the team of six graduate students approached the AOCD project, the first question was whether a community of people with disabilities exists within Johnston County. The answer to this question was not immediately apparent. The team discovered that at least one community does exist, composed mostly of parents of children and adults with disabilities. As a result, the team defined the community as people with disabilities and their families.

The first official contact with Johnston County was through a windshield tour coordinated by the team's preceptor (field advisor), Lawrence Shockey. The team drove through several towns within the county and walked around downtown Smithfield, the county seat. The windshield tour provided an opportunity to observe many different facets of the community including landscape, population density, types of housing, businesses, transportation, geography, houses of worship, restaurants, racial and ethnic diversity, etc. Lawrence Shockey served as narrator and guide, sharing his perspective and providing background information on the county.

Following the windshield tour, the team decided to learn more about disabilities in general; so they identified and attended several activities that provided vital instruction in relating to the community. These events included a meeting of the North Carolina Disability Action Network in Raleigh, the Assistive Technology Expo in Raleigh, and an in-depth training on the Americans with Disabilities Act conducted by the two preceptors. Armed with a better understanding of issues for people with disabilities in general, the team began to engage with groups and events that were specific to Johnston County, including attending a First in Families

meeting, a meeting of the Johnston County Disability Awareness Council, the first meeting to organize The Arc of Johnston County, and several Special Olympics events. After attending these events, each team member recorded field notes detailing the activities which took place, observations and conversations, and her response to these activities.

Identifying and Reviewing Secondary Data Sources

The secondary data collection process was focused on public information that is relevant to and illustrative of the conditions, history, social and physical environments, and events that influence and affect people with disabilities in Johnston County. Individual team members researched areas such as demographics, housing, education, health, and services and then reported their findings back to the team. Most secondary data were available through Internet sources, but team members also reviewed newspaper articles, press releases, and collected printed materials and verbal anecdotal information from service providers and agencies.

Limitations of Secondary Data

The team had some difficulty finding sources with information specifically about people with disabilities in Johnston County. In these cases, North Carolina data were used to fill in the gaps in the county-level secondary data. Although demographic information was found through the Census, some of the detailed information about other areas affecting people with disabilities such as health, housing and income were supplemented with state level data.

Identifying and Recruiting Participants for Key Informant Interviews and Focus Groups

A detailed application addressing all issues related to the protection of human subjects was submitted to the Institutional Review Board (IRB) at the School of Public Health and approved prior to conducting any formal research activities. This document outlined the protocol for identifying and recruiting study participants, costs and benefits of participation, obtaining informed consent, maintaining confidentiality, and public release of data. Copies of the approval

letter and all IRB approved consent forms are included in Appendix E. Separate consent forms were created for service providers, community members with disabilities, and community /family members. A separate consent form was prepared to allow participation by people with legal guardians. Large print and Braille versions of forms were available, as was a sign language interpreter, but no participant requested them.

Participants for this study included community members with disabilities^{*}, family members of people with disabilities living in Johnston County, and service providers serving the county. The team defined a key informant as someone who was knowledgeable about people, activities, and attitudes in Johnston County and who could speak for the community about issues related to life in general and specifically to people with disabilities. These individuals were located through several means. Service providers and community leaders in Johnston County were identified through public records or listings and through the assistance of the preceptors and other community member referrals. Individuals who identified themselves as activists and advocates within the disability community by attending and participating in group meetings were also approached directly.

People with disabilities and family members of people with disabilities were first identified by a preceptor, service provider, or other community member who used the Recruitment Consent form (see Appendix E-4) to connect the potential interviewee with the team. A team member followed up to request participation in the study. In conducting interviews the team recognized that not all people with disabilities were capable of providing informed consent (particularly some people with cognitive disabilities), to make this

^{*} Although the team had IRB approval to interview community members without disabilities, they ended up focusing on people in the other three categories only. All data reflect these three perspectives.

determination, the team relied on preceptors, service providers in the community, and family members to help decide which individuals with disabilities to interview.

Developing, Pretesting, and Using Guides for Interviews and Focus Groups

The team's original interview and focus group guides were based on those used by the 2003-2004 AOCD team that worked with people with disabilities in Raleigh.²² The team modified these guides to include items specific to Johnston County. Different guides were created for interviews and focus groups, with separate guides for service providers, community members with and without disabilities, and family members of people with disabilities.[^] The guides were submitted to the IRB and approved with the original application (see Appendix F). Interview guides were pilot tested with both preceptors (using the service provider and the family member interview guides) to solicit their feedback and to identify problem areas. The process of editing the interview guides continued throughout the AOCD.

Primary Data Collection: Conducting Key Informant Interviews

The team conducted a total of 32 key informant interviews – 15 service providers, 10 family members (two were interviewed together), 7 community members with disabilities, and 1 community member without disabilities (who was classified as a service provider for the purpose of analysis). One team member conducted the interview and another team member took notes, which were handwritten or typed on a laptop with the permission of the participant. Each interview was tape recorded with the participant's permission.

Conducting Focus Groups

Team members conducted two focus groups. The first focus group was conducted with 7 family members of people with disabilities recruited through community events attended by team members. The second focus group was conducted with 7 people with disabilities recruited

[^] Although the team had an interview guide for community members without disabilities, they ended up focusing on people in the other three categories only.

through a service provider. Each lasted close to 90 minutes and was attended by three team members. One team member facilitated the group and the other two were note takers. Both focus groups were tape recorded with the permission of the participants.

Data Transcription, Coding, and Analysis

After transcribing several interviews, the team developed data analysis procedures. Specifically, they coded the transcripts inductively, letting the themes emerge from the data instead of from a predetermined codebook, and from these transcripts they identified and categorized major thematic areas.

The coding process began with a verbatim transcript that the note taker produced from an audio recording of the interview or focus group, and the interviewer initially coded the transcript. Coding involved highlighting sections of the transcript and writing a word or phrase in the margin that summarized that passage. The codes corresponded to recurring ideas and issues that emerged from the interviews, and served as a mechanism to identify and organize prominent themes and related information. Two team members served as the coding sub-committee and coded all transcripts a second time in order to ensure reliability of the coding scheme, and address any discrepancies that arose between the first and second coding. These two team members were also responsible for creating three databases, one each for community members, family members, and service providers, into which data segments were entered according to categorical and thematic areas (i.e. transportation, support for parents, education, etc.). From these databases, team members were able to easily access data segments related to specific themes.

Limitations of Primary Data

As described in the introduction, the AOCD team defined the population for this study as people with disabilities and their families, with family members often serving as both informal

caregivers and volunteer service providers. The team discovered that there was a great deal of overlap in the roles individuals played in the community: Family members and people with disabilities were also service providers. For the purpose of analysis, interviewees were asked which category they preferred.

Because of the focus on people with disabilities and their families, the team was unable to explore issues for the elderly and had limited participation from adults with disabilities who lived on their own without connections to family members. The team regrets that they were not able to recruit diverse racial and ethnic groups, particularly from the growing Latino community (see Appendix B-4 for a summary of demographics). The team recognizes the importance of these populations and suggests that future AOCD teams look at issues for people with disabilities in these populations.

Selecting the Community Advisory Board

The purpose of the Community Advisory Board (CAB) was to create a sense of ownership within the community of the AOCD in general and of the forum specifically. The team considered several factors in the selection of the CAB. First, it was important that all interview categories were represented. Second, the team wanted to recruit individuals who were movers and shakers within the community, able to generate interest, mobilize participants, and access resources. Finally, the team wanted to include people who demonstrated an understanding of the goals of the project and an ability to work with others.

The team asked all interviewees whether they would be interested in being on the CAB and provided them with a brief description of what this would entail. As the project progressed and the team gained some initial volunteers, they were more intentional about seeking a balance of expertise and perspective. The final composition of the CAB is detailed in the forum section.

Section V: Conclusion and Next Steps

The goal of the team's AOCD project was to gain a better understanding of the cultural, social, economic, and health experiences of people with disabilities and their families. The purpose of this document is to summarize the AOCD process, present findings, and suggest future action steps to improve life for people with disabilities in Johnston County. This document is intended to serve as a resource to the people of Johnston County as they work to improve the lives of people with disabilities.

The timing of this project was ideal in that the team entered Johnston County when a great deal of momentum was already building around issues for people with disabilities. During their time in Johnston County, the team was able to watch the community coming together to develop solutions to major challenges and to join them in this ongoing work. This was especially evident after the severe cutbacks in JCATS transportation services in the fall of 2004 and after the change in the leadership of Special Olympics in February 2005.

Initially, the team was unsure how to discover a community of people with disabilities in Johnston County. However, over time the team found many committed individuals and groups, working to support people with disabilities. At the community forum, the team observed these separate groups come together to develop action steps to create change, and it became evident that a community that supports people with disabilities does exist in Johnston County.

The great potential for change in Johnston County was demonstrated by the number of participants who attended the forum and by their energy, enthusiasm, and the action steps they generated. Based on these action steps, the interviews, and observations, the team makes the following recommendations for the future:

- Continue to recognize the need to combine resources and work together in order to effect change; the team supports the suggestion of a community member that a forum become an annual event in the county.

- Continue to cooperate and share resources among service providers, family members and community members with disabilities in Johnston County.
- Develop a central location where community members can learn more about services and resources available in the county; Make a comprehensive list of resources and services for people with disabilities available at this center.
- Train and educate parents about available services and disability rights.
- Consider the needs of people with disabilities (housing, schools, recreation, and employment) in future planning efforts and county development.
- Create a plan to address the transportation needs of all residents.
- Continue to invest in the establishment and growth of The Arc of Johnston County, NC as they work to empower and improve the lives of children and adults with disabilities. The subcommittees of The Arc can be a valuable resource for future organizing efforts.
- Develop a program in which key community members shadow people with disabilities to increase awareness and understanding.
- Build a village, an assisted living community in which adults with disabilities are able to live independently from their parents and pursue their goals in a supported environment.

The team encourages The Arc of Johnston County and the contact people identified during the community forum to work together and take the lead in following up on these recommendations and all the action steps generated during the forum.

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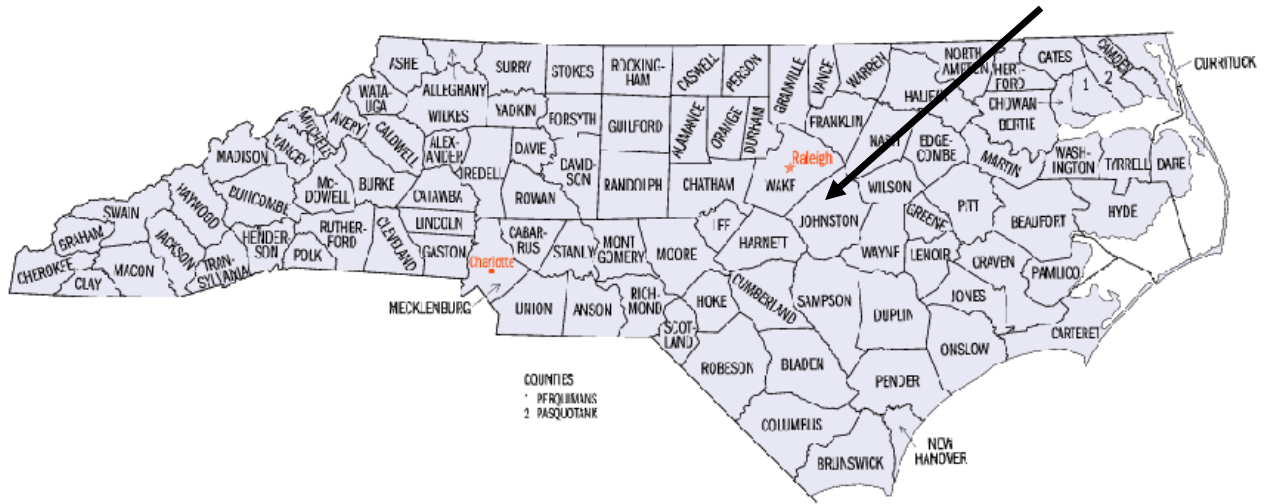
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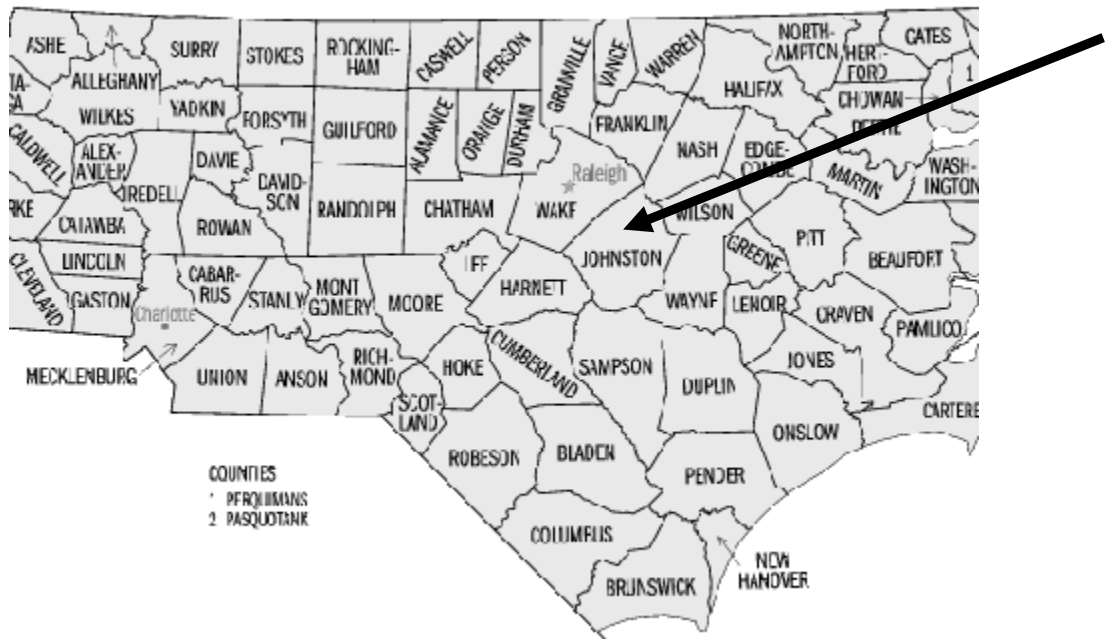
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Appendices

Appendix A-1: Map of North Carolina

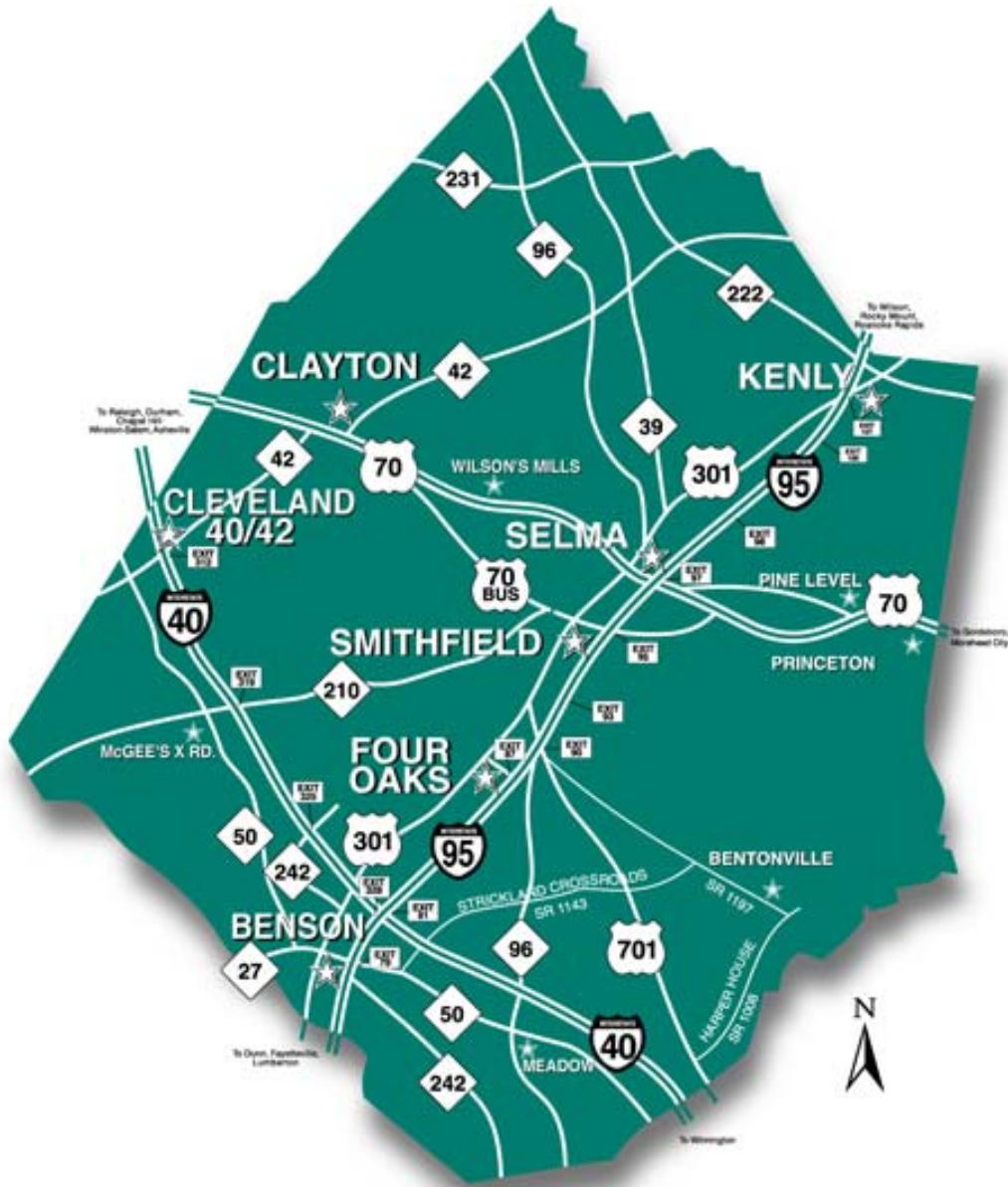


Map of North Carolina, with arrow pointing to Johnston County. Source: U.S. Census Bureau
<<http://quickfacts.census.gov/qfd/maps/scaled37-90.gif>>



Enlarged map of North Carolina, with arrow pointing to Johnston County. Source: U.S. Census Bureau
<<http://quickfacts.census.gov/qfd/maps/scaled37-90.gif>>

Appendix A-2: Map of Johnston County



Courtesy of Johnston County Visitors Bureau

Appendix B-1: List of Themes from Interviews

The following themes were developed by the two-person coding subcommittee based on analysis of interview and focus group transcripts. These themes were presented to the Community Advisory Board in mid-April, and they decided to focus on six of these (bolded below) for the community forum. Note: the words in brackets indicate which of the people interviewed touched on that theme. For example, “all” means family members, community members with disabilities and service providers mentioned that theme.

1. **Public schools in Johnston County are not doing an adequate job of serving some children with disabilities. [all]**
2. There are mixed feelings about inclusion: ideologically, it is a good concept, but we need to ensure that the unique needs of children with disabilities are being met. [all]
3. There is a shortage of state, federal, and county funding for services for people with disabilities that results in long waitlists and limited insurance coverage for disability-related care (i.e. demand exceeds supply). [all]
4. Family members and service providers are cautiously optimistic that the situation for people living with disabilities in Johnston County is starting to change for the better, but it’s a very slow process. [all]
5. **There is a critical need for better public transportation options for people living with disabilities. [all]**
6. **Parents of people living with disabilities need more support services and support groups. [all]**
7. There is a need for better job opportunities that are a good fit for my child with disabilities. [family members]
8. **There is a critical need for assisted living facilities and better housing options for people living with disabilities. [all]**
9. Medical services are consistently improving, but there are not adequate specialty services for people living with disabilities in Johnston County, including specialists, physical therapy, occupational therapy, and speech therapy. Most families have to travel outside of the county to access these services. [all]
10. Family members are tired and stressed from always having to fight for services and resources in Johnston County. [family members]
11. In order to get services, parents and consumers need to know their rights, fight for them, and be advocates. [all]
12. **People living with disabilities and their families have limited knowledge of services, and service providers have a difficult time making consumers aware of their services. [all]**

13. Transitions are especially difficult for people with disabilities; from pre-school to school and from high school to independence (i.e. disrupts routine, have to learn a new system and new service providers). [all]
14. There are mixed feelings about all of the growth in Johnston County: most people are happy about new people, new ideas, and new services coming in, but are concerned about the rapid rate of growth and that it might take away from the rural, friendly atmosphere of Johnston County. [all]
- 15. The community needs to be more aware of the needs and abilities of people living with disabilities. [all]**
16. Johnston County is a large, rural county; most services are available in Clayton and Smithfield, which requires many families to drive a long distance to receive services. [all]
17. The growing Latino community in Johnston County is difficult to serve due to language barriers and different cultural beliefs and understanding of disabilities. [service providers]
18. There is a general resistance to change in Johnston County; the “good ‘ol boys network” in Johnston County is a barrier to meeting the needs of people with disabilities; the legislature is not educated or not responsive. [all]

Appendix B-2: Frequencies of Topics (Domains)

The following is a table showing the number of times each type of interviewee mentioned particular topics (domains). The first six domains were selected by the Community Advisory Board to serve as the focus of discussion and the creation of action steps at the Community Forum on April 28, 2005. It is important to note, that this list is not exhaustive; people touched on other topics, but less often. In addition, it is possible that more people mentioned some of these domains, and they were not coded by the team members.

Topic area	Family Members (out of 16)*	Service Providers (out of 16)^	Community Members with Disabilities (out of 14)*	Total (out of 46)*
Transportation	11	11	12	34
Schools	11	3		14
Support for Parents	11	2		13
Housing	7	10	7	24
Community Awareness	5	11	5	21
Knowledge of Services	7	9	2	18
Advocacy	10	7	2	19
Employment	9	9	8	26
Special Olympics	11	1	8	20
Health Care	7	6	6	19
Funding/Expenses/Insurance	5	12		17
Inclusion	6	3	1	10
Transition from high school to independence	4	5		9
Transition from pre-school to school	2	3		5
Latinos hard to reach		9		9
Rural areas hard to reach		5		5

* Totals include individuals from both interviews and focus groups. Also two family members were interviewed together, so counts from them are combined.

^ One community member was analyzed as a service provider.

Appendix B-3: List of Interviews by Type

Interview ID	Date	Time	Location	Interviewer	Notetaker	Interview Type
1SP	11/8/2004	12:30 PM	Raleigh	Kristin	Katya	Service Provider
2SP	12/14/2004	10:00 AM	Raleigh	Colleen	Katie	Service Provider
3SP	12/15/2004	1:00 PM	Smithfield	Kristin	Katya	Service Provider
4SP	12/15/2004	4:00 PM	Smithfield	Kim	Colleen	Service Provider
5SP	1/17/2005	2:00 PM	Raleigh	Katie	Emily	Service Provider
6SP	1/28/2005	11:00 AM	Smithfield	Colleen	Katya	Service Provider
7SP	1/28/2005	2:30 PM	Smithfield	Katie	Colleen	Service Provider
8SP	2/8/2005	9:00 AM	Clayton	Emily	Kim	Service Provider
9SP	2/11/2005	9:30 AM	Raleigh	Colleen	Kim	Service Provider
10SP	2/11/2005	2:30 PM	Smithfield	Kim	Katie	Service Provider
11SP	2/17/2005	2:00 PM	Selma	Katya	Emily	Service Provider
12SP	3/2/2005	9:30 AM	Clayton	Katie	Emily	Service Provider
13SP	3/25/2005	1:00 PM	Smithfield	Kristin	Colleen	Service Provider
14SP	3/31/2005	2:00 PM	Phone	Katya	Colleen	Service Provider
15SP	4/8/2005	11:00 AM	Smithfield	Kim	Emily	Service Provider

Interview ID	Date	Time	Location	Interviewer	Notetaker	Interview Type
1CM*	2/11/2005	2:30 PM	Smithfield	Katya	Kristin	Community Member/Svc Provider
2CMD	2/11/2005	4:00 PM	Benson	Kristin	Katya	Community Member w/ Disability
3CMD	2/18/2005	3:00 PM	Four Oaks	Katya	Colleen	Community Member w/ Disability
4CMD	2/24/2005	1:30 PM	Smithfield	Kristin	Emily	Community Member w/ Disability
5CMD	2/24/2005	3:30 PM	Clayton	Emily	Kristin	Community Member w/ Disability
6CMD	3/2/2005	1:00 PM	Durham	Kristin	Kim	Community Member w/ Disability
7CMD	3/4/2005	9:00 AM	Benson	Kim	Katya	Community Member w/ Disability
8CMD	3/25/2005	11:00 AM	Benson	Colleen	Kristin	Community Member w/ Disability

* For the purposes of analysis, this person was considered a Service Provider

Interview ID	Date	Time	Location	Interviewer	Notetaker	Interview Type
1FM	1/11/2005	1:00 PM	Raleigh	Katie	Emily	Family Member
2FM	1/11/2005	2:00 PM	Raleigh	Emily	Katie	Family Member
3FM	1/28/2005	11:30 AM	Smithfield	Emily	Katie	Family Member
4FM	2/2/2005	11:00 AM	Garner	Katie	Emily	Family Member
5FM	2/4/2005	10:00 AM	Durham	Katya	Kristin	Family Member
6FM	2/17/2005	1:30 PM	Princeton	Colleen	Kristin	Family Member
7FM ⁺	2/18/2005	4:30 PM	Benson	Colleen	Katya	Family Member
8FM ⁺	2/18/2005	4:30 PM	Benson	Colleen	Katya	Family Member
9FM	3/11/2005	2:00 PM	phone	Katya	none	Family Member
10FM	3/23/2005	10:30 AM	Clayton	Katie	Kim	Family Member

⁺ These two people were interviewed together, so the interview was counted as one.

Interview ID	Date	Time	Location	Interviewer	Notetaker	Notetaker	Interview Type
FM FG1	2/26/2005	1:00 PM	Smithfield	Katie	Kim	Katya	Family Member
CMD FG1	3/4/2005	12:00 PM	Smithfield	Colleen	Emily	Kristin	Community Members w/ Disabilities

Appendix B-4: Interviewee Demographics

This appendix summarizes the demographics of community members with disabilities and family members who were interviewed for this project. Service providers were not asked for demographic data. Due to the focus on people with disabilities and their families, the team did not interview elderly people with disabilities.

Demographics of Community Members with Disabilities

- The team interviewed a total of 14 community members with disabilities.
 - 7 were interviewed individually
 - 7 participated in a focus group interview
- More men than women were interviewed.
- Of 14 community members with disabilities interviewed,
 - 8 were white
 - 4 were black
 - 2 were other minorities

The following table summarizes data about the ages of community members with disabilities who were interviewed:

Age Range	18-59 years old
Average Age (mean)	31 years old
Median Age	26 years old
Percent between 18 and 28 years old	64 %

Demographics of Family Members

- The team interviewed a total of 17 family members.
 - 10 were interviewed individually
 - 7 participated in a focus group interview
- More women than men were interviewed.
- All identified themselves as either white, Caucasian or Anglo.

The following table summarizes data about the ages of family members who were interviewed.

Age Range	29-63 years old
Average Age (mean)	48 years old
Median Age	48 years old

Living with Disabilities in Johnston County: A Working Forum



Date: Thursday, April 28, 2005

Time: 6:00-9:00 pm

Forum Location:

Centenary United Methodist Church

(104 E. Market St. in downtown Smithfield on the corner of Market St. (Highway 70) and Second Street)

The Purpose of this Working Forum is to:

- **Share and discuss the strengths and challenges of living with disabilities in Johnston County.**
- **Connect the community with services and resources.**
- **Develop action plans for the future.**

People with disabilities, their families and friends, service providers, and concerned citizens are invited to attend.

Anyone needing special assistance or accommodations, please RSVP by April 21, 2005.

Call us at 1-866-610-8273 ext.1 or email us at teamjc2005@yahoo.com.



Food & Entertainment



Appendix C-2: Forum Invitation Letter (Interviewees)

Team Johnston County
Phone: (919) 966-5542, ext. 1
Toll free phone: (866) 610-8273
E-mail Address: teamjc2005@yahoo.com

April 6, 2005

Dear

Thank you again for being willing to share your thoughts and experiences about what life is like for people with disabilities living in Johnston County and their families. We have spoken with nearly fifty people in your community and are eager to share with you what we have found, based on our interviews and focus groups. You may remember hearing that we were planning to host a community forum in Johnston County in April. We are very pleased to invite you to attend this event.

The community forum will take place on Thursday, April 28th from 6:00 – 9:00 pm at the Centenary United Methodist Church in Smithfield. Centenary United Methodist Church is located at the corner of Market Street (US70 Business) and Second Street in Downtown Smithfield. The address is 140 E. Market St., Smithfield, NC 27577.

We are calling this a “working forum” because we are hoping to discuss the strengths and challenges for people living with disabilities in Johnston County and their families and to connect people with services and resources. First, we will present the information we have gathered from all of you. Then, we will break into small groups and brainstorm ways to address the issues that you have raised and to plan for the future. Finally, we will create action steps that will allow the community to move forward in making Johnston County an even better place for people with disabilities and their families.

We hope that you are able to attend this event and invite you to bring your friends and family as well (see enclosed flier). This forum is for you and for others who care about these issues. Unfortunately we do have limited space so we will be calling you in a few days to follow up and make sure we know how many people will be coming.

If you have any questions, please do not hesitate to get in touch with us by phone or by e-mail (see above). In the meantime, thank you again for your commitment to persons with disabilities, their families, and the Johnston County community.

Sincerely,

Katie and Colleen

Appendix C-3: Forum Invitation Letter (General)

April 13, 2005

Name
Address
City, State Zip

Dear ,

We are writing to let you know about some exciting work that is going on in Johnston County for people with disabilities and their families. We are a team of six graduate students from the School of Public Health at the University of North Carolina-Chapel Hill who have been conducting an Action Oriented Community Diagnosis in Johnston County. Our goal was to learn more about what life is like for people with disabilities and their families by attending community events and conducting interviews and focus groups with nearly fifty service providers, family members, people with disabilities, and community members. In partnership with our community advisory board, we are currently planning a community forum to discuss the issues raised in these interviews and focus groups. We are very pleased to invite you to attend this event.

The community forum will take place on Thursday, April 28th from 6:00 – 9:00 pm at the Centenary United Methodist Church in Smithfield. Centenary United Methodist Church is located at the corner of Market Street (US70 Business) and Second Street in Downtown Smithfield. The address is 140 E. Market St., Smithfield, NC 27577.

We are calling this a “working forum” because we are hoping to discuss the strengths and challenges for people living with disabilities in Johnston County and their families, to share information about services and resources, and to plan for the future. First, we will present the information we have gathered from our interviews and focus groups. Second, we will break into small groups and brainstorm ways to utilize the strengths in Johnston County to address the issues that have been raised. Finally, we will create action steps that will allow the community to move forward in making Johnston County a better place for people with disabilities and their families.

We greatly value your participation in this event and hope that you are able to attend. As an additional incentive, food and entertainment will be provided. If you have any questions, please do not hesitate to get in touch with us by phone or by e-mail (see below). In the meantime, thank you again for your commitment to people with disabilities, their families, and the Johnston County community.

Sincerely,

Katie Emmet and Colleen Blue
Team Johnston County and the Johnston County Community Advisory Board
Phone: (919) 966-5542, ext. 1
Toll free phone: (866) 610-8273
E-mail Address: teamjc2005@yahoo.com

A WORD OF THANKS

TO OUR DONORS:

Centenary United Methodist Church
First in Families
St. Mary's Grove Baptist Church
(Women's Auxiliary & Men's Brotherhood)

TO OUR SUPPORTERS:

Carolina Pride Sportswear
Gandolofo's New York Delicatessen
Golden Corral of Smithfield
Hinson's Printing
La Parilla Restaurant
Marla's Restaurant
NC Division of Services for the Deaf and
the Hard of Hearing
Riverside Coffee Company
SC Sports
Snapple, Inc.
The Arc of Johnston County, N.C., Inc.
This and That
University of North Carolina at Chapel Hill
White Swan

TO OUR ENTERTAINMENT:

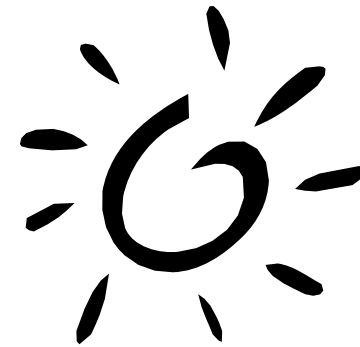
The Harmonics
Heather Coletti
The Williamson Brothers

SPECIAL THANKS TO OUR COMMUNITY ADVISORY BOARD

**Comments? Feedback?
TeamJC2005@yahoo.com**

Living with Disabilities in Johnston County:

A Working Forum



WELCOME!

**April 28, 2005
6:00 pm**

**Centenary United Methodist Church
Smithfield, NC**

Strengths of Johnston County

- ❖ Residents of Johnston County typically come together and help each other in times of need.
- ❖ Community members are optimistic about positive change for people with disabilities and their families.
- ❖ Community members foresee great potential to mobilize resources and awareness with the recent formation of The Arc of Johnston County, NC.
- ❖ Community members enjoy the slower pace, safety, rural charm, and friendly faces that characterize Johnston County.
- ❖ Special Olympics is a wonderful program and source of support for people with disabilities and their families.

Themes for Small Group Discussion

- 1) There is a critical need for better public **transportation** options for people living with disabilities.
- 2) Public **schools** in Johnston County are not meeting the needs of students with disabilities.
- 3) Parents of people living with disabilities need more support services and **support groups**.
- 4) There is a critical need for assisted living facilities and better **housing** options for people living with disabilities.
- 5) The **community needs to be more aware** of the needs and abilities of people living with disabilities.
- 6) People living with disabilities and their families have limited **knowledge of services**, and service providers have a difficult time making consumers aware of their services.

Schedule of Events



- | | |
|---------------|--|
| 6:00-6:55 pm: | Check-in, dinner, resource tables, & entertainment |
| 6:55-7:00 pm: | Welcome |
| 7:00-7:30 pm: | Introductions, explanation of project & presentation of findings |
| 7:30-7:40 pm: | Break into small groups |
| 7:40-8:20 pm: | Small group discussions |
| 8:20-8:30 pm: | Reconvene in main auditorium |
| 8:30-9:00 pm: | Report back on action steps |
| 9:00 pm: | Thanks and closing remarks |



Check it out!

A copy of our final report will be available at:
www.hsl.unc.edu/Phpapers/phpapers.cfm

Appendix C-5: Small Group Intro and Ground Rules

Johnston County Forum Small Group Discussions

Introduction

My name is _____, and I will be facilitating the small group discussion about _____. This is _____ who will be taking notes during our discussion. As a reminder, the theme is _____.

Just to let you know what we will be doing, first we will listen to a story (I will read a quote) and then I will ask you some questions about it. Next, we will come up with action steps (to address the theme of _____). I am here to help guide the discussion and make sure that we finish by 8:20, so that we can meet everyone else downstairs to report back the action steps.

I'd like to refer everyone to the Ground Rules that will also help us stay on time and guide the discussion:

- Please talk one at a time.
- Please do not have side conversations.
- Because we have a lot to cover, I may interrupt you at some point so that we can keep moving and avoid running out of time.
- We want this to be a safe environment, so please respect the opinions of others.

Does everyone agree with the ground rules?

Reminders:

- Designate someone to report back the action steps at the forum.
- Designate a contact person for other people at the forum who want to get involved with addressing this issue. Ask if the person is willing to share their name and contact information at the forum.
- Give the contact person's name and number to (_____).

Appendix C-6: Small Group Discussion Techniques

This appendix contains both a general description of the methods* used by team members to guide discussion during the small group sessions at the community forum and the specific methods used in each small group session. The three methods are: Force Field Analysis, SHOWED, and ORID.

Force Field Analysis

Force Field analysis is a method for facilitating a small group in the creation of action steps related to a proposed change. It involves the identification and evaluation of the forces that either help or hinder a proposed change, with a gradual narrowing of focus to specific hindering forces (barriers) that can be lessened or helping forces that can be strengthened to help create the change. Force Field analysis is a useful technique when small group participants already understand the issues being discussed and are ready to create action steps.

Steps:

1. Identify the current situation and decide on a goal to be achieved.
2. Write the current situation in a box in the center of the paper, and the goal on the far right.
3. Group members brainstorm all the helping forces and hindering forces (barriers) that affect the present situation, and/or the ability to move toward the goal. Helping forces are written on the left side of the current situation box, and hindering forces are written on the right.
4. Group members discuss the importance of each helping and hindering force.
5. Draw arrows connecting the forces and the current situation box; longer arrows indicate more important forces (Note, arrows for hindering forces are drawn to point away from the goal and arrows for helping forces point toward the goal).
6. Group members identify the helping or hindering force on which they want to focus. This becomes the current situation on a new piece of paper.
7. Repeat the process 1-2 times, until the group arrives at a goal specific enough for which concrete action steps can be created.
8. Group members brainstorm action steps and responsibility for each action step is assigned to a group member.

SHOWED

SHOWED is a small group discussion technique that is intended to begin with an understanding of the underlying causes of a situation end in action steps. It is a useful technique when the topic of discussion has not been addressed by group members previously and when the root causes of the problem have not been articulated. SHOWED is an acronym whose letters stand for different steps in the process of guiding the discussion.

Steps:

1. Use a trigger to begin the discussion. A trigger might be a poem, a skit, a quote, a video clip, or a story that captures the essence of the situation the group is about to discuss.
2. Ask group members recommended SHOWED questions to guide the discussion from a common understanding of what is happening in the trigger, to why it is happening, and finally to what can be done about it.

* Source for the general description of methods: Boland, M., Isaacs, K., Kunkel, J., Mangum, A., Mersereau, D. & Myers, A. (2004). *An Action-Oriented Community Diagnosis for people living with disabilities in Raleigh, NC*. Retrieved October 25, 2004 from <http://www.hsl.unc.edu/PHpapers/RaleighDisabilities.pdf>

Appendix C-6: Small Group Discussion Techniques

Sample SHOWED Questions:

- S (SEE): What do you see in this picture?
- H (Happening): What is happening?
- O (Our): How does this relate to our lives?
- W (Why): What causes this?
- E (Evaluation): How are we part of the problem?
- D (Do): What can we do about this?

ORID

ORID is a small group discussion technique that is intended to begin with an understanding of a situation end in action steps. It is similar to SHOWED in many ways, but focuses less on root causes of problems and has a simpler structure. ORID is also an acronym whose letters stand for different steps in the process of guiding the discussion.

Steps:

1. Use a trigger to begin the discussion. A trigger might be a poem, a skit, a quote, a video clip, or a story that captures the essence of the situation the group is about to discuss.
2. Ask group members recommended ORID questions to guide the discussion from a common understanding of what is happening in the trigger, to why it is happening, and finally to what can be done about it.

Sample ORID Questions:

- O (Objective): What do you see in this picture?
- R (Reflective): What was your first response?
- I (Interpretive): What is this poem (or other trigger) about?
- D (Decisional): What change is needed? What can we do about these issues?

Appendix C-6: Small Group Discussion Techniques

Theme 1 Small Group Discussion: Transportation

Introduction

Introduce note-taker and myself.

Briefly review ground rules.

The need for better public transportation for people living with disabilities in Johnston County was the most common issue that was raised in our interviews and focus groups with family members, community members, and service providers. There is unanimous agreement that there is not adequate public transportation to all areas of Johnston County. In the next 45 minutes, our goal is to identify some key action steps that will lead to addressing this challenge in Johnston County, and to identify community members who are willing to serve as a point person for addressing these action steps in the community. We will share these action steps with the whole group at the conclusion of our discussion, so we will also be looking for someone who would be willing to report our action steps to the group.

Force Field Analysis

To get us started, here is a statement of the theme, the current situation in Johnston County:

THERE IS A CRITICAL NEED FOR BETTER PUBLIC TRANSPORTATION OPTIONS FOR PEOPLE LIVING WITH DISABILITIES IN JOHNSTON COUNTY.

Can you think of factors that would **HELP** to improve the current situation?

Can you think of **BARRIERS** to improving the current situation?

Appendix C-6: Small Group Discussion Techniques

Theme 2 Small Group Discussion: Schools

Trigger:

Michelle was born with an injury to the right side of her brain, and walks with a limp. Every morning she walks with her friends to catch the bus to school. Michelle is really glad that she has friends from her neighborhood in her class, yet some of the kids who do not know Michelle sometimes make fun of how slow she walks.

One day, during P.E., Michelle's class was picking teams for a kickball game. As always, Michelle was one of the last people to be picked, and some of the kids groaned when they found out that she would be playing on their team. When it was Michelle's turn to kick the ball, some of the kids made fun of Michelle.

When they got back to the classroom, Michelle started to rip up her papers and kick her chair. The teacher didn't know why Michelle was acting this way, but looked around at the other students who were getting restless. She thought to herself, "What should I do? How do I balance the needs of this child with the needs of the entire class?"

SHOWED Questions:

What words or images stood out as Tammy read this story?

- Literally, what are you hearing in this story?

How does Michelle feel when she gets back from the playground?

How does the teacher feel?

How does this story relate to our lives?

Why does this problem exist?

How are we part of the problem?

How can we be part of the solution?

What can we do?

What would be our first step?

Who is willing to volunteer to do the first step?

Will someone volunteer to **report back** the action steps to everyone downstairs?

Will someone volunteer to be a **contact person** for others at the forum who are interested in helping with some of these action steps?

Appendix C-6: Small Group Discussion Techniques

Theme 3 Small Group Discussion: Support for Parents

Good evening and thank you for coming. My name is Katie, and I will be facilitating our small group discussion about the need for more support for parents/caregivers of people with disabilities in Johnston County.

Just to let you know what we will be doing, I will begin by reading a quote from one of our family member interviews and then ask you some questions about it. Next, we will brainstorm action steps to address the issues we have discussed. I am here to help guide the discussion and make sure that we finish by 8:20, so that we can meet everyone else downstairs to report back on our action steps.

I'd like to refer everyone to the Ground Rules that will also help us stay on time and guide the discussion:

- Please talk one at a time.
- Please do not have side conversations.
- I may interrupt you at some point so that we can keep moving and avoid running out of time.
- We want this to be a safe environment, so please respect the opinions of others.

Does everyone agree with the ground rules?

Trigger:

When they first told us, your child is mentally retarded, and after that I heard everything else they said, but I was so numb. We drove back home and after 48 hours of crying . . .

I didn't know what that really meant. And I had this board of psychologists and education people and I'm sitting here and I don't understand the terminology that they use. I don't really understand what they're saying. So I go to the library. That's the first place I went to, because I didn't know where else to start, to educate myself. What do they mean he's retarded? What do they mean he'll never read? The library didn't have a whole lot in it. In fact they had one book . . . There is not a lot out there.

ORID Questions:

1. What words or phrases jump out at you from this quote?
2. How is this parent feeling?
3. How did you feel when I was reading this quote?
4. What is going on in this situation?
5. How does this relate to your experience in Johnston County?
6. What change is needed?
7. What specific action could we take to address these issues?
8. What is one area that we would like to focus on now?
9. What will be our first steps?
10. Who would like to volunteer to be a contact person for other people who are interested in finding out more about support for parents in JC?
11. Who would be willing to give the report back to the large group?

Appendix C-6: Small Group Discussion Techniques

Theme 4 Small Group Discussion: Housing

Trigger:

Lucille was heading for the check-out line at the grocery store when she saw Janice. The two women had recently met at a support group meeting for parents of children with disabilities.

“Hi Janice, great to see you again. How are you and how is your son?” Lucille asked.

“Hello Lucille. Well my son is doing great! He’s really excited about finishing up high school,” said Janice. “But the end of school is getting me thinking about the future. I wonder if he’ll ever get to move out and live on his own like the other kids are doing.”

“I know what you mean,” said Lucille sympathetically. “My son is forty and he still lives with his father and me. I know he wants to be more independent, but there is just so much he can’t do on his own. He has trouble managing his money. I don’t think he’d remember to take his medicine without me. And besides, living on his own is so expensive!”

“So what can we do?” asked Janice.

“I don’t know,” replied Lucille shaking her head. “He’s too young for a nursing home and he can’t live on his own. His father and I just aren’t getting any younger. I just don’t know what he’ll do when we’re gone.”

ORID questions:

O (objective): What words or phrases in this story stood out to you?

R (reflective): What was your first response to this story?
Or How does this story make you feel?

I (interpretive): What issues does this story bring up for you?

D (decisional): What can we do about these issues?
What specific actions can we take?
What are the next steps?
Which are more important and changeable?
Which can we do first?

Appendix C-6: Small Group Discussion Techniques

Theme 5 Small Group Discussion: Community Awareness

Trigger:

“I think in some cases people probably look at people with disabilities differently than they look at a person who doesn’t have a disability. They might think ‘They can’t do that,’ but really they can. Maybe they have a disability, but sometimes people with disabilities are just as smart as normal people, and sometimes they can do the job just as good, or sometimes even better.”
-Community Member

Objective:

- **“What are some key ideas presented in the quote?”**
-“What words or phrases stuck out for you?”

Reflective:

- **“How did the quote make you feel?”**
-“What was your first response?”

Happening:

- **“How do you think people with disabilities feel?”**
- **“How do you think people without disabilities feel?”**
(clarify—people unfamiliar with ppl w/ disabilities)

Interpretive:

- **“What issues did the quote bring up for you?”**
-“What is the quote about?”
-“Why are they important?”
- **“What areas can these issues affect?”**
(ok to prompt for experiences if time is going well or they are having trouble)

Decisional:

- **“What change is needed?”**
- **“What specific actions can we take to address these issues?”**
- **“What would be our first step?” (volunteers?)**

Appendix C-6: Small Group Discussion Techniques

Theme 6 Small Group Discussion: Knowledge of Services

Trigger:

“The biggest impact on us has been the not knowing what’s going on type of feeling, of not knowing who to contact...We’ve been given little information on the services/resources in the community or even statewide. That’s why I did the advocacy training. I absolutely knew nothing about anything that was available in the county or statewide because that was never given to us through the agencies we’ve worked with. Every step of the way, we’ve had to take the initiative, and it’s been very taxing time-wise and financially, just having to do all that leg-work ourselves, rather than having an agency that we could rely on.”

- Family Member

Questions:

1. What words or images stuck out in this quotation?
2. What feelings is this parent expressing?
3. How does this quotation make you feel?
4. How does this relate to your experience in Johnston County? What issues does this bring up for you?
5. What causes these issues to exist in Johnston County?
6. What can be done to address these issues?
7. What specific actions can we take to address these issues in Johnston County? What would be our first step?

Appendix C-7: Agencies with Resource Tables at Forum

Occupational Course of Study

Chris Alberti, Transition Coordinator
Johnston County Schools
230 Equity Drive
Smithfield, NC 27577
919-934-4361 ext. 352
Fax: 919-989-9380
Chrisalberti@johnston.k12.nc.us

Family Support Network of Eastern NC

Candace Lang, Parent Coordinator
CandaceLangFSN@hotmail.com

Modern Woodmen

Cheri Thomas, Representative
cheri-thomas@nc.rr.com
919-332-8197

Division of Services for the Deaf and the Hard of Hearing

319 Chapanoke Road
Raleigh NC 27603
1-800-851-6099
<http://dsdhh.dhhs.state.nc.us>

Division of Services for the Blind

2601 Mail Service Center
309 Ashe Ave
Raleigh, NC 27699-2601
1-866-222-1546
<http://www.dhhs.state.nc.us/dsb/>

JobLink Career Center – ESC

Ellen Parrish, Employment Counselor
224 Peedin Rd
Smithfield, NC 27577
919-934-0536
<http://www.joblinkcc.com>

Johnston County Disability Awareness Council

P.O. Box 2493
Smithfield, NC

Ellen Parrish, Chairperson
eparrish@compart.org
Dianne Loy, Vice Chair
bloym@highstream.net
Janet Davis, Secretary
Janet.J.Davis@ncmail.net
Kathy Ward, Treasurer
Kathy.Ward@ncmail.net
Renee Hinton, Immediate Past Chair
Renee.Hinton@ncmail.net

Johnston County Autism Society

Becky Kinkade
hyrpwr@earthlink.net

First in Families of Johnston County

Susan Price, Resource Coordinator
fifjc@earthlink.net

The Arc of Johnston County Inc.

<http://www.thearcofjohnstoncountync.org/>

Aubry Williamson, President
919-820-3023
Dianne Loy, Vice President
919-697-0202
Dale Bender, Board of Directors Member
919-618-3537

Appendix C-8: Action Steps

Transportation

Goal: To improve public transportation for people living with disabilities in Johnston County.

The following action steps were generated:

1. Compile contact information for county commissioners and legislators to distribute to members in the community who would like to contact local government officials.
2. Contact JCATS in order to collect specific information about how their administration, funding, and contract process works.
3. Contact the Department of Transportation to get the contact information for individuals that are responsible for funding allocation and administration in Johnston County.
4. Start a petition to collect signatures, and submit to local government.
5. Gather information to determine how people with disabilities in Johnston County can qualify for transportation benefits under the Elderly and Disabled Transportation Assistance Program (EDTAP).
6. Research other funding opportunities for transportation for people with disabilities.
7. Contact service agencies in Johnston County to collect data regarding the need for transportation among their clients with disabilities.

Education

The following action steps were generated:

1. Advocate and challenge the legislature for more funding.
2. Train and educate parents about services available to their children.
3. Bring parents and schools together via workshops and the Arc.
4. Contact the Arc of Johnston County, NC to set up an education committee.

Support for Families

Goal: Create a comprehensive list of services and resources for people with disabilities in Johnston County

Related action steps:

1. Begin an informal listserv – group facilitator will e-mail a summary of the ideas generated in the discussion to all small group participants.
2. Contact the Arc about setting up a discussion board for parents on the Arc website.
3. Explore possibility for bumper stickers to facilitate communication about disability issues.
4. Attend training offered by the Family Support Network (FSN) for parents who want to become support parents (all group members were invited to participate).
5. Connect parents to services, resources, and each other through the FSN newsletter

Housing

Long-range goal: Design housing with the multiple life needs of people with disabilities in mind (i.e. transportation, employment and recreation).

Related action steps were:

1. Research planned communities to come up with examples of successful designs.
2. Conduct a community assessment to find specific housing needs of people with disabilities.
3. Learn more about Circle of Friends and Life Plans to help define the community's needs.

Short-range goal: To help individuals with disabilities to live independently using currently available resources.

Related action steps were:

1. Identify current resources from organizations like Mental Health and First in Families.
2. Research possible housing models in Clayton and Raleigh.

3. Find out if there are partnering resources to help people with disabilities find roommates.
4. Run a column in a local newspaper to educate the community about the lives and needs of people with disabilities.

Community Awareness

Goal: To develop a program in which key community members shadow people with disabilities to increase awareness and understanding.

The group developed the following action steps related to the development of a shadowing program:

1. Form a steering committee for the program, and select a leader of the committee.
2. Contact key community members (County Commissioners, Board of Education members and employers) to participate in the program.
3. Contact a variety of county agencies that serve people with disabilities to find a diverse group of people to be shadowed.
4. Coordinate publicity to bring media attention to the program.

Knowledge of Services

1. Create a comprehensive list of services and resources available in Johnston County and organize the list so that parents can easily find the information that they need.
2. Develop a class at Johnston Community College to inform parents of the services available in the county and to help parents navigate the system to access the services.
3. Ask the local newspapers to write a weekly story spotlighting an agency that serves people with disabilities in Johnston County.

Appendix D-1: Team Observations

Event Type	Event Name	Date	Number of Team Members who wrote Field Notes
Agency Meetings (4)	North Carolina Disability Action Network (NC-DAN)	10/16/2004	2
	First in Families-Johnston County (2)	11/22/2004, 2/28/2005	2
	Johnston County Disability Awareness Council	12/15/2004	2
Functions Sponsored by Service Providers (1)	Assistive Technology Exposition	11/4/2004	5
	Tour- Johnston County Health Department	4/8/5005	2
Functions Sponsored by Community Members (3)	Arc Meeting	1/10/2005	3
	Special Olympics Practices/Events (4)	1/6/2005, 1/27/2005, 2/3/2005, 2/12/2005	2
	Special Olympics Johnston County Local Games	4/15/2005	3
Team Meetings (3)	Windshield Tour (Guided by Lawrence Shockey)	10/7/2004	6
	Team Meeting/Viewing of documentary, <i>Rolling</i>	10/18/2004	6
	ADA Training at Alliance of Disability Advocates	11/13/2004	6
Interviews (32)	Interviews	11/8/2004- 4/8/2005	6
Focus Groups (2)	Focus Group with Family Members	2/26/3005	3
	Focus Group with CM with Disabilities	3/4/2005	3
General Observations	Experiences in the community	10/7/2004- 4/28/2005	5

Appendix E-1: IRB Approval Letter

School of Public Health
Institutional Review Board on Research Involving Human Subjects

FORM FOR MODIFICATION OF APPROVED PROPOSALS
Send to: School of Public Health IRB
UNC-CH, CB # 7400, Chapel Hill, NC 27599-7400

<i>For IRB Use</i>	
ID	_____
Rec'd	_____
Expires	_____
Full/Exp	_____

Date of last approval: 09/20/2004

Date of this application: 10/13/2004
Date of re-submission: 11/11/2004

Title of Project: Action-Oriented Community Diagnosis of Johnston County, North Carolina

Name of Principal Investigator: Katie Emmet

Names of co-investigators: Colleen Blue, Kim Chapman, Eugenia Eng, Kristin Hoeft, Allison Myers, Katya Roytburd, and Emily Wurth
*(If the principal investigator is a student, give the name of the faculty advisor.
If new staff have been added to the project, provide their UNC-CH ethics certificates.)*

For the PI:
Department: Health Behavior and Health Education CB #: 7440
(If this is not your mailing address, please provide one)

Position: Student

Phone #: (919) 966-5542 Fax #: (919) 962-0142 Email Address: emmet@email.unc.edu

Funding source or sponsor:

___ federal ___ state ___ industry ___ foundation ___ UNC X Other (*Specify*): No funding source

Are minors involved? [] yes [X] No

Signature of Principal Investigator:_____

Signature of Advisor, if PI is a student._____

Note: By signing, you are indicating that you have read and approved the attached application for IRB review, and that you have reviewed and approved the student's research project.

This form is to request approval for changes to projects already approved by the IRB. The modification application process involves describing the existing project and the intended change. Since IRB membership, regulations, and precedents change, it is important that the modification application be complete but still concise. For the benefit of new IRB members who have never seen your protocol and for those who haven't seen it since last review, it is important to provide the same information that was in the original application, *including any past IRB-approved changes to the original protocol*, as well as the proposed changes to the protocol. Expand the area under each question below to provide space for an adequate response.

→ ***Unless all contact with subjects has concluded, enclose current consents, fact sheets, and/or assents, and all instruments used with subjects.***

1. Research protocol.

The purpose of this research project is to understand the cultural, social, economic, and health experiences of persons with disabilities and their families residing in Johnston County, North Carolina in order to identify future directions that will enable the larger Johnston County community and persons with disabilities within the community, to gain competency that leads to improved health status for persons with disabilities. Community members with and without disabilities, family members of a person with a disability (“family members”), and service providers will be asked to participate in the AOCD.

As part of the AOCD, interviews and focus groups will be conducted with community members (including persons with and without disabilities and family members of persons with disabilities), and service providers. Subjects will be asked similar, yet perspective appropriate questions (see attached interview & focus group guides). Colleen Blue, Kim Chapman, Katie Emmet, Kristin Hoeft, Katya Roytburd, and Emily Wurth will conduct interviews and facilitate focus groups.

Focus groups will be planned with members of the community and service providers. The research team will attempt to schedule and hold focus groups with willing individuals already participating in group meetings. They will be facilitated by one member of the research team, with another team member taking notes. Focus group ground rules will be explained to all participants, highlighting the fact that nothing which is discussed within the focus group may be shared with anyone outside the group. Focus group guides are included in Appendix D. In addition, for the sake of efficiency and to maintain privacy, demographic and background information generally collected as part of the interview will be collected in written form in the focus group setting (if appropriate) using the Demographic/Background Information Sheet found in Appendix G.

The research team will conduct personal interviews for research participants who may not have the time, inclination or ability to participate in a focus group. Interviews will not be conducted with those people who have already participated in a focus group; nor will persons already interviewed be participants in a focus group. One student team member will conduct the interview, with another team member taking notes. Interview guides are included in Appendix C.

The research team estimates that up to 50 subjects will participate either in one focus group or one interview each. Both focus groups and interviews will be tape recorded, with the consent of participants prior to taping. Participants will also be informed that they may turn off the tape recorder at any time during the group.

Results of the interviews and focus groups will then be summarized and made available to community members. Identifying information will not be linked to statements made by community members and service providers during interviews or focus groups. Only aggregate information or quotes without identifying information will be used. Characteristics, such as age, sex, ethnicity, and number of years residing in Johnston County may be used when summarizing data.

Is the protocol an analysis of existing data (your protocol never included contact with human subjects)?
[] Yes [X] No. *If yes, go to 10.*

Are you still collecting data from human subjects or have any contact with subjects?

[X] Yes [] No. *If no, go to 15.*

2. Description of human subjects.

The human participants for this study include community members with and without disabilities and family members of persons with disabilities residing in Johnston County, North Carolina and service providers working in this county. Approximately 15 service providers and 25 community members will participate in this research project. Minority status, sex, or health status are not relevant factors in selecting participants. Only individuals who are over 18 years of age who agree to participate will be interviewed. All persons who wish to participate and are able to give informed consent will be included in the research. Persons deemed incapable of providing informed consent by a person qualified to make this judgement will be excluded.

For the purpose of this AOCD, disability will be defined according to the definition used by the Americans with Disabilities Act passed in 1990: “a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or a record of such an impairment, or a person who is perceived by others as having such an impairment.” We intend to speak with a cross section of persons with disabilities rather than restricting ourselves to any specific type of disability. We expect our AOCD may include persons with mobility impairment, sensory disability, and cognitive disability.

We do not anticipate that any of our subjects will be unable to give informed consent. We are aware that added care must be taken to ensure that persons with cognitive limitations possess the receptive and expressive language skills necessary for understanding the project and voluntarily agreeing to participate in it. As public health students, we do not possess the clinical skills for assessing the level of cognitive impairment. Therefore, we will rely on our preceptors and service providers in the community to guide us in determining which persons may not be appropriate for this project. Whenever possible, we will consult with service providers who have a relationship with the potential subject in order to determine eligibility.

We feel that it is very important not to exclude persons who may have legal guardians but are willing and able to participate in an interview of focus group. As specified above, special care will be taken to protect the right of all subjects with cognitive disabilities who participate in our project, regardless of whether or not they have a legal guardian. They will be referred to us by qualified individuals (preceptors, service providers, family members) who will help us to judge the willingness and ability of each subject to express their views as well as their capacity for informed consent. Interview and focus group guides will be modified as appropriate to meet the needs of these participants.

The following individuals will serve as preceptors for our AOCD and will guide us in identifying individuals who will be appropriate interview and focus group subjects. Lawrence Shockey is an Interpreter Specialist and Information Support Services Consultant for the Raleigh Regional Resource Center (A Service for the Deaf and Hard of Hearing). He is a certified ASL interpreter and has worked in the mental health field and as an advocate for persons with disabilities. He has also been a volunteer for the NC Counsel for Developmental Disability, serves as the interim chair for First in Family of Johnston County, and is a licensed foster parent. Rene Cummins is the director of the Alliance of Disability Advocates, Center for Independent Living in Raleigh, North Carolina. She has served as a preceptor for AOCD projects in the past and has experience conducting interviews and focus groups with a wide range of populations with disabilities. In addition to service providers within the community, our preceptors will use their expertise in this field to guide us in the ethical conduct of our research.

3. Methods of recruitment

Service providers and community leaders in Johnston County will be identified through public records or listings and with the assistance of our preceptors. They will be contacted by the research team about their availability and interest in participating in this study.

Potential informants who are community members (persons with and without disabilities and family members of persons with disabilities) will be identified by a preceptor, community leader, or service provider. Using the Recruitment Consent

form (see Appendix E), the person who identified the community member will then contact them via telephone or in writing about their availability and interest in participating in this study. The preceptor/community leader/service provider who is recruiting will explain that no decision about participation will be made until all questions have been answered satisfactorily by the research team. It will also be explained to potential informants that the care and services which they may receive in Johnston County will not be affected in any way should they choose not to participate in the project, nor will their service provider be notified of their choice. Only after a potential participant has agreed to be contacted will a member of the research team contact that person to request participation in an interview or focus group.

Other potential informants will be identified by original participating community members. Using the Recruitment Consent form (see Appendix E), the original participant will ask the potential informant if he or she is willing to be contacted regarding possible participation in the project. Only after a potential informant has agreed to be contacted will a member of the research team contact that person to request participation in an interview or focus group.

Finally, participants may be recruited through already existing group meetings which team members may attend. In this case, the information in the Recruitment Consent Form will be provided to the people attending the meeting and they will be given the opportunity to contact a member of the research team if they are interested in participating in the project.

All persons referred to the research team will be considered potential participants. Eligible subjects include all persons able and willing to provide informed consent. In the case of persons with mental disabilities, we will rely on the professional judgement of our preceptors and local service providers to assess whether or not the individual has the receptive and expressive skills necessary to complete an interview.

4. Compensation and costs.

Interviewees will not be compensated or given inducements for their participation. The only costs to participants will be the time spent in the interviews. These interviews are expected to last approximately one hour. The only compensation for focus group participants may be food and/or refreshments provided at the focus group. Focus groups will last approximately 90 minutes.

5. Risks to subjects.

Foreseeable physical, psychological, and social risks of participating in this research project are expected to be few. Specific risks for service providers may include negative assessments of the community and the provision of services in the community. If such information were divulged it might place subjects at risk for losing his or her job or may affect the political career of a community leader. However, no names will be attached to interviews and the data will be kept confidential in a locked cabinet. The questions for the participants do not include probing of information that might be considered offensive, threatening, or degrading. Interviews and focus groups will focus primarily on the strengths, weaknesses, and directions for development for the communities. All participants have the option of withdrawing from participation of an interview or focus group at any time. Though participants of focus groups will remain anonymous, they may know one another. To protect them from any risk of statements being shared outside the group, participants will be given instructions not to talk about or share the information discussed during the focus group outside of that focus group session. Participants will sign the consent form indicating that they agree to abide by these guidelines. Additionally, focus group participants will be told that they have the option of not answering any question(s) and of turning off the tape recorder at any time. All focus groups and interviews will be conducted in a private setting. If the need for medical or psychological help arises, preceptors will be consulted for referral information.

6. Benefits.

A written summary of the cultural, social, economic, and health experiences of persons with disabilities residing in Johnston County and their family members and the strengths and needs of the Johnston County community will be made available to the community - including community leaders, community members with and without disabilities, family members, and service providers. This summary will also include future directions for the community to pursue. A community forum to share the results of this community diagnosis will be planned to benefit the entire Johnston County community. This forum will allow community members to participate directly in the community development process and provide them with an opportunity to voice their concerns and to create change.

7. Procedures for obtaining informed consent.

Prior to any interview or focus group, the informed consent form detailing the study and their participation will be communicated to participants in the manner which is easiest for them to understand (ex: signed, read in Braille, read aloud, read to themselves). In addition, a copy will be given to participants to keep for their records. Written consent will be obtained from all participants prior to conducting interviews and focus groups. A separate consent form has been prepared for persons participating in interviews (see Appendix A) and focus groups (see Appendix B). In addition, interview and focus group informed consent forms have been tailored according to subgroup (community members with disabilities, family members and community members without disabilities, and service providers). Note that the same consent form will be used for family members and community members without disabilities. Interview and focus group forms will be modified as needed for persons with sensory disabilities. For example, a consent form with identical content but printed in a larger font will be made available to persons with low vision. Other accommodations such as sign language interpreting will be provided as needed.

We do not anticipate that any of our subjects will be unable to give informed consent. We are aware that added care must be taken to ensure that persons with cognitive limitations possess the receptive and expressive language skills necessary for understanding the project and voluntarily agreeing to participate in it. As public health students, we do not possess the clinical skills for assessing the level of cognitive impairment. Therefore, we will rely on our preceptors and service providers in the community to guide us in determining which persons may not be appropriate for this project. Whenever possible, we will consult with service providers who have a relationship with the potential subject in order to determine eligibility.

We feel that it is very important not to exclude persons who may have legal guardians but are willing and able to participate in an interview or focus group. As specified above, special care will be taken to protect the right of all subjects with cognitive disabilities who participate in our project, regardless of whether or not they have a legal guardian. They will be referred to us by qualified individuals (preceptors, service providers, family members) who will help us to judge the willingness and ability of each subject to express their views as well as their capacity for informed consent. A separate interview and focus group consent form has been prepared for persons with legal guardians and will be signed by both the legal guardian and the participant (see Appendix A.1 and B.1) prior to their participation in an interview or focus group. Interview and focus group guides will be modified as appropriate to meet the needs of these participants.

Participants will be informed that releasing certain characteristics (such as ethnicity, age, sex, and number of years residing in Johnston County) will be used only for summarizing data and not linked to any statements they made. The researchers will also make clear that potential subjects who choose not to participate will not be denied access to services. They will then be asked if they have any questions, all of which will be answered by the researchers. Participants will be asked to provide written consent by reading the three statements at the end of each consent form and indicating their agreement to participate with their signature. Focus group participants will be informed that they can use a made-up name during the focus group but must sign their real name on the consent form. All participants will also be provided with a copy of the consent form for their own records. Additional persons may attend an interview or focus group in order to provide medical or social support for the participants. These individuals will be asked to sign the Confidentiality Statement found in Appendix H indicating that they understand their role as an observer not a participant and their willingness not to repeat anything that is shared outside the group. The researchers will then proceed with the interview or focus group.

8. Confidentiality of the data.

Names and other personal identifiers of all participants in interviews and focus groups will be stored separately from their collected data. Though names and addresses will be collected using the Project Interest Form (see Appendix F), they are used only to obtain informed consent and to invite participants to a community forum at the end of the study. Participants will sign the informed consent prior to participation but will not be required to provide their names and addresses on the Project Interest Form if they are not interested in being contacted. Information such as age, ethnicity, and number of years living in the community will only be used to summarize data and will not be linked to specific quotes or information.

provided by participants. All documents and materials will be kept in a locked file cabinet to which only the research team members have access. Identifying information and collected data will be stored in separate files. The research team will destroy all notes, documents, and materials related to data collection in May 2005 at the completion of the AOCD process.

Special care will be taken when presenting data not to allow persons with easily recognized characteristics (i.e. there may only be one blind person within a town) to be identified by their fellow community members.

Audiotaping is preferred for all interviews and focus groups. Permission will be secured from participants prior to recording, and participants will be informed of their right to turn off the tape recorder at any time during the interview. Audiotapes will be erased or destroyed after data analysis has been completed in May 2005. Until erasure, audiotapes will also be kept in a locked file cabinet to which only the research team members have access.

9. Public release of data.

We do not plan to publish this data. However, a summary of the data collected during this project will be presented in a final document. The purpose of this study is to fulfill course requirements for HBHE 240/241: Action Oriented Community Diagnosis. This summary document will be made available to the community online through the UNC Health Sciences Library web site (and may be available through other venues as well such as the Johnston County Health Department or the public library).

→ Go to 15.

If your protocol is an analysis of existing data (no contact with subjects), answer the following:

10. Description and source of secondary data. What is the source of the data (e.g., Medicaid records)? What are the data about (e.g., hospital admission records for patients)? Secondary data include tissue samples.

11. Personal identifiers in secondary data. Do the data contain personal identifiers? Does the data contain elements that might permit deductive disclosure of a subject's identity? Does a name/ID linking file exist? If so, who has access to this file?

12. Public data? If the data are publicly available to anyone without restriction, state that. If not, describe access restrictions and any confidentiality agreements required by the provider of the data.

13. Confidentiality of the data. Describe procedures for protecting the confidentiality of the data.

14. Public release of data. Will data from the study be released to other investigators at some future time? If yes, what additional steps will be taken to protect confidentiality?

15. Provide a complete description of proposed modifications. Be sure to include information on how modifications will affect risk, benefits, and confidentiality to subjects. Explain any changes in subject pool, recruitment or incentive. If questionnaires or other instruments have been revised, please highlight the changes on the instrument(s). If applicable, include new consents/assents/fact sheets.

The purpose of this modification is to make the general block application (IRB Number 04-2377) approved 09/20/04 specific to the work which our research team will be doing in Johnston County, North Carolina. Please refer to highlighted sections of the above application for specific additions.

A brief summary:

1. Research protocol: The target population is identified as persons with disabilities living in Johnston County, North Carolina and the community as a whole. Members of the Johnston County research team from UNC are named. An estimated number of subjects is given (up to 50 participants).

- 2. Description of Human Subjects:** Disability is defined according the Americans with Disabilities Act passed in 1990. Informed consent issues specific to persons with cognitive limitations are addressed. Preceptors for the project are identified and described.
- 3. Methods of Recruitment:** Protocol is outlined for recruiting of subjects using the Recruitment Consent Form. Potential participants will indicate a willingness to be contacted before being pursued by a member of the research team with the exception of service providers and community leaders who will be contacted directly through public records or listings.
- 5. Risk to subjects:** Participants will be informed about confidentiality rules within the focus group setting and will sign the informed consent indicating their agreement to abide by these guidelines.
- 6. Benefits:** Information has been made specific to Johnston County.
- 7. Informed Consent:** Written informed consent will be obtained from all subjects prior to participation. Separate consent forms have been prepared for interviews and focus groups and have been tailored to match the needs of specific sub-groups. Issues specific to obtaining consent in this population such as cognitive limitations and sensory disabilities have been addressed.
- 8. Confidentiality:** Data will be confidential. Names and addresses will be collected for the purposes of obtaining informed consent and for providing information to participants about other AOCD activities within the community. Participant names/addresses will be stored separately from their data.
- 9. Public release of the data:** Information has been made specific to Johnston County.

Appendix E-2: Interview Consent Forms

Interview Consent Form for Community/Family Members

Would you like to participate in an AOCD of your community?

WHAT IS AOCD? AOCD means Action-Oriented Community Diagnosis. AOCD is a research assessment designed to understand the cultural, social, economic, and health experiences of individuals living in Johnston County. The purpose of AOCD is to better understand the experiences of persons with disabilities living in Johnston County and their families.

WHY ARE YOU PARTICIPATING IN AOCD?

You are being asked to participate because we want to gain perspective from individuals with disabilities, family members, community members, and service providers on Johnston County's strengths and needs regarding services and supports for people with disabilities. Someone in your community identified you as a person who can talk about the views of your community.

WHAT WILL YOU BE ASKED TO DO?

You will be asked to participate in an individual interview with two team members from the UNC School of Public Health. The interview consists of a series of questions about life in your community. An example of a general question is, "What is it like to live in your community?" There are no wrong answers or bad ideas, just different opinions. If you do not feel comfortable answering a question or do not have an opinion, just let us know. We are interested in your perspective as a community member and/or family member. The interview will be one-time only and will take about 60 minutes of your time.

If you agree to participate in the interview, we will record your responses on a piece of paper. Also, with your permission, we would like to tape record the discussion to make sure we do not miss anything. Only members of our group will listen to the tapes. The tapes will be erased after our study is over. You can ask us to turn off the tape recorder at any time. If you decide to participate in this interview, you will be asked to sign an "informed consent" form. Signing the form means that you understand the purpose of the AOCD project and what you will be asked to do during the project. It also means that you understand that you can stop taking part in the project at any time.

WHAT ARE THE BENEFITS AND RISKS OF MY PARTICIPATION?

You will have the opportunity to share your thoughts about Johnston County. Your participation may help to make things better in your community over time. You will not be paid to participate in this interview. There are minimal physical, psychological, or social risks associated with participating in this study. However, one potential risk may arise if you make any negative comments about your community or individuals within the community, and that information is disclosed, your reputation may be affected. We will do the best we can to protect you from this risk by keeping all data in a locked file cabinet at the School of Public Health. In addition, your name will never be attached to anything you say. Your decision to take part in this study will not influence any of the services you receive or might receive. You can say yes or no to our request to be interviewed, and it will not change any services to which you are entitled.

WHAT ARE THE COSTS OF TAKING PART IN THIS PROJECT?

There are no costs for participating in the study other than your time spent during this interview.

WHAT WILL WE DO WITH THE INFORMATION THAT WE GATHER?

The team will summarize the information gathered from interviews and focus groups (small groups assembled to identify and discuss key issues in the community) and present it in both written and verbal form to your community at a community forum.

YOUR PARTICIPATION IS VOLUNTARY AND CONFIDENTIAL.

If you agree to participate in this study, please understand that your participation is voluntary (you do not have to do it). Any information that you provide will remain confidential. Your name and address may be collected, but it will not be used in any way in the research study or linked to your responses. It will only be used to invite you to attend the community forum.

Every effort will be taken to protect the identity of the participants in this study. However, there is no guarantee that the information cannot be obtained by legal process or court order. Information such as age and number of years residing in Johnston County may be gathered during the interview. These descriptive characteristics are collected only to help summarize our data. When we report the data, all identifying information will be removed. Your responses and comments will not be linked to you. The only people with access to all data are the members of the student team and the faculty advisors. All notes and audiotapes containing your interview responses will be stored in a locked cabinet at the School of Public Health and will be destroyed in May 2005 when the study is over.

CAN YOU REFUSE OR STOP PARTICIPATION?

Yes. You are free to stop participating at any time. You can refuse to answer any questions. During the interview you may ask that the recording be stopped at any time.

WHO IS IN CHARGE OF THIS PROJECT? HOW CAN I CALL THEM?

This is a student project being conducted under the supervision of our faculty advisor, Eugenia Eng. If you have any questions about this project and/or you wish to withdraw at any time, you may contact graduate student, Katie Emmet, or Eugenia Eng. Their contact information follows:

Katie Emmet (919) 966-5542
UNC School of Public Health
Campus Box 7440, Chapel Hill, NC 27599-7440

Eugenia Eng (919) 966-3909
UNC School of Public Health
Campus Box 7440, Chapel Hill, NC 27599-7440

This project has been approved by the UNC-CH Public Health Institutional Review Board, Office of Human Research Ethics. If you have questions about your rights as a study participant, or are dissatisfied at any time with any aspect of this study, you may contact -- anonymously, if you wish -- the Public Health Institutional Review Board, Office of Human Research Ethics, University of North Carolina at Chapel Hill, CB # 7400, Chapel Hill, NC 27599-7400, or by phone 919-966-3012. You may call collect.

Agreement Statement:

By signing this consent form, I agree that I have read and understand the information presented here, and I freely give my consent to participate in the Action-Oriented Community Diagnosis.

(your signature and date)

(team member signature and date)

Thank you!

Appendix E-2: Interview Consent Forms

Interview Consent Form for Community Member with a Disability Would you like to participate in an AOCD of your community?

WHAT IS AOCD? AOCD means Action-Oriented Community Diagnosis. AOCD is a research assessment designed to understand the cultural, social, economic, and health experiences of individuals living in Johnston County. The purpose is to better understand the experiences of persons with disabilities living in Johnston County and their families.

WHY ARE YOU PARTICIPATING IN AOCD?

You are being asked to participate because we want to gain perspective from individuals with disabilities, family members, other community members, and service providers on Johnston County's strengths and needs regarding services and supports for people with disabilities. Someone in your community identified you as a person who can talk about the views of your community as a whole.

WHAT WILL YOU BE ASKED TO DO?

You will be asked to participate in an individual interview with two team members from the UNC School of Public Health. The interview consists of a series of questions about life in your community. An example of a general question is, "What is it like to live in your community?" There are no wrong answers or bad ideas, just different opinions. If you do not feel comfortable answering a question or do not have an opinion, just let us know. We are interested in your perspective as a community member with a disability. The interview will be one-time only and will take about 60 minutes of your time.

If you agree to participate in the interview we will record your responses on a piece of paper. Also, with your permission, we would like to tape record the discussion to make sure we do not miss anything. Only members of our group will listen to the tapes. The tapes will be erased after our study is over. You can ask us to turn off the tape recorder at any time. If you decide to participate in this interview, you will be asked to sign an "informed consent" form. Signing the form means that you understand the purpose of the AOCD project and what you will be asked to do during the project. It also means that you understand that you can stop taking part in the project at any time.

WHAT ARE THE BENEFITS AND RISKS OF MY PARTICIPATION?

You will have the opportunity to share your thoughts about Johnston County. Your participation may help to make things better in your community over time. You will not be paid to participate in this interview. There are minimal physical, psychological, or social risks associated with participating in this study. However, one potential risk may arise if you make any negative comments about your community or individuals within the community, and that information is disclosed, your reputation may be affected. We will do the best we can to protect you from this risk by keeping all data in a locked file cabinet at the School of Public Health. In addition, your name will never be attached to anything you say. Your decision to take part in this study will not influence any of the services you receive or might receive. You can say yes or no to our request to be interviewed, and it will not change any services to which you are entitled.

WHAT ARE THE COSTS OF TAKING PART IN THIS PROJECT?

There are no costs for participating in the study other than your time spent during this interview.

WHAT WILL WE DO WITH THE INFORMATION THAT WE GATHER?

The team will summarize the information gathered from interviews and focus groups (small groups assembled to identify and discuss key issues in the community) and present it in both written and verbal form to your community at a community forum.

YOUR PARTICIPATION IS VOLUNTARY AND CONFIDENTIAL.

If you agree to participate in this study, please understand that your participation is voluntary (you do not have to do it). Any information that you provide will remain confidential. Your name and address may be collected, but it will not be used in any way in the research study or linked to your responses. It will only be used to invite you to attend the community forum.

Every effort will be taken to protect the identity of the participants in this study. However, there is no guarantee that the information cannot be obtained by legal process or court order. Information such as age and number of years residing in Johnston County may be gathered during the interview. These descriptive characteristics are collected only to help summarize our data. When we report the data, all identifying information will be removed. Your responses and comments will not be linked to you. The only people with access to all data are the members of the student team and the faculty advisors. All notes and audiotapes containing your interview responses will be stored in a locked cabinet at the School of Public Health and will be destroyed in May 2005 when the study is over.

CAN YOU REFUSE OR STOP PARTICIPATION?

Yes. You are free to stop participating at any time. You can refuse to answer any questions. During the interview you may ask that the recording be stopped at any time.

WHO IS IN CHARGE OF THIS PROJECT? HOW CAN I CALL THEM?

This is a student project being conducted under the supervision of our faculty advisor, Eugenia Eng. If you have any questions about this project and/or you wish to withdraw at any time, you may contact graduate student, Katie Emmet, or Eugenia Eng. Their contact information follows:

Katie Emmet (919) 966-5542	Eugenia Eng (919) 966-3909
UNC School of Public Health	UNC School of Public Health
Campus Box 7440, Chapel Hill, NC 27599-7440	Campus Box 7440, Chapel Hill, NC 27599-7440

This project has been approved by the UNC-CH Public Health Institutional Review Board, Office of Human Research Ethics. If you have questions about your rights as a study participant, or are dissatisfied at any time with any aspect of this study, you may contact -- anonymously, if you wish -- the Public Health Institutional Review Board, Office of Human Research Ethics, University of North Carolina at Chapel Hill, CB # 7400, Chapel Hill, NC 27599-7400, or by phone 919-966-3012. You may call collect.

Agreement Statement:

By signing this consent form, I agree that I have read and understand the information presented here, and I freely give my consent to participate in the Action-Oriented Community Diagnosis.

(your signature and date)

(team member signature and date)

Thank you!

Appendix E-2: Interview Consent Forms

Interview Consent Form for Service Providers

Would you like to participate in an AOCD of your community?

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WHY ARE YOU PARTICIPATING IN AOCD?

You are being asked to participate because we want to gain perspective from individuals with disabilities, family members, other community members, and service providers on Johnston County's strengths and needs regarding services and supports for people with disabilities. Someone in your community identified you as a person who can talk about the views of your community as a whole.

WHAT WILL YOU BE ASKED TO DO?

You will be asked to participate in an individual interview with two team members from the UNC School of Public Health. The interview is made up of a series of questions about life in your community. An example of a general question is, "What is it like to live in your community?" There are no wrong answers or bad ideas, just different opinions. If you do not feel comfortable answering a question or do not have an opinion, just let us know. We are interested in your perspective as a service provider in Johnston County. The interview will be one-time only and will take about 60 minutes of your time.

If you agree to participate in the interview we will record your responses. Also, with your permission, we would like to tape record the discussion to make sure we do not miss anything. Only members of our group will listen to the tapes. The tapes will be erased after our study is over. You can ask us to turn off the tape recorder at any time. If you decide to participate in this interview, you will be asked to sign an "informed consent" form. Signing the form means that you understand the purpose of the AOCD project and what you will be asked to do during the project. It also means that you understand that you can stop taking part in the project at any time.

WHAT ARE THE BENEFITS AND RISKS OF MY PARTICIPATION?

You will have the opportunity to share your thoughts about the future of Johnston County. Your participation will provide useful information that can be used by Johnston County to plan and improve services available for its residents. You will not be paid to participate in this interview. There are minimal physical, psychological, or social risks associated with participating in this study. However, one potential risk may arise if you make any negative comments about the community or the services you provide in the community, and that information is divulged, you may be at risk of losing your job. Such information could also affect any political career you may choose to pursue. We will do the best we can to protect you from this risk by keeping all data in a locked file cabinet at the School of Public Health. In addition, your name will never be attached to anything you say.

WHAT ARE THE COSTS OF TAKING PART IN THIS PROJECT?

There are no costs for participating in the study other than your time spent during this interview.

WHAT WILL WE DO WITH THE INFORMATION THAT WE GATHER?

The team will summarize the information gathered from interviews and focus groups (small groups assembled to identify and discuss key issues in the community) and present it in both written and verbal form to your community at a community forum.

YOUR PARTICIPATION IS VOLUNTARY AND CONFIDENTIAL.

If you agree to participate in this study, please understand that your participation is voluntary (you do not have to do it). Any information that you provide will remain confidential. Though your name and address may be collected, it will not be used in any way in the research study or linked to your responses. It will only be used to invite you to attend the community forum.

Every effort will be taken to protect the identity of the participants in this study. However, there is no guarantee that the information cannot be obtained by legal process or court order. Information such as age and number of years residing in Johnston County may be gathered during the interview. These descriptive characteristics are collected only to help summarize our data. When we report the data, all identifying information will be removed. Your responses and comments will not be linked to you. The only people with access to all data are the members of the student team and the faculty advisors. All notes and audiotapes containing your interview responses will be stored in a locked cabinet at the School of Public Health and will be destroyed in May 2005 when the study is over.

CAN YOU REFUSE OR STOP PARTICIPATION?

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WHO IS IN CHARGE OF THIS PROJECT? HOW CAN I CALL THEM?

This is a student project being conducted under the supervision of our faculty advisor, Eugenia Eng. If you have any questions about this project and/or you wish to withdraw at any time, you may contact graduate student, Katie Emmet, or Eugenia Eng. Their contact information follows:

Katie Emmet (919) 966-5542	Eugenia Eng (919) 966-3909
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Agreement Statement:

By signing this consent form, I agree that I have read and understand the information presented here, and I freely give my consent to participate in the Action-Oriented Community Diagnosis.

(your signature and date)

(team member signature and date)

Thank you!

Appendix E-2: Interview Consent Forms

Interview Consent Form for Community Member with a Disability Would you like to participate in an AOCD of your community?

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If you agree to participate in the interview we will record your responses on a piece of paper. Also, with your permission, we would like to tape record the discussion to make sure we do not miss anything. Only members of our group will listen to the tapes. The tapes will be erased after our study is over. You can ask us to turn off the tape recorder at any time. If you decide to participate in this interview, you will be asked to sign an "informed consent" form. Signing the form means that you understand the purpose of the AOCD project and what you will be asked to do during the project. It also means that you understand that you can stop taking part in the project at any time.

WHAT ARE THE BENEFITS AND RISKS OF YOUR PARTICIPATION?

You will have the opportunity to share your thoughts about Johnston County. Your participation may help to make things better in your community over time. You will not be paid to participate in this interview. There are minimal physical, psychological, or social risks associated with participating in this study. However, one potential risk may arise if you make any negative comments about your community or individuals within the community, and that information is disclosed, your reputation may be affected. We will do the best we can to protect you from this risk by keeping all data in a locked file cabinet at the School of Public Health. In addition, your name will never be attached to anything you say. Your decision to take part in this study will not influence any of the services you receive or might receive. You can say yes or no to our request to be interviewed, and it will not change any services to which you are entitled.

WHAT ARE THE COSTS OF TAKING PART IN THIS PROJECT?

There are no costs for participating in the study other than your time spent during this interview.

WHAT WILL WE DO WITH THE INFORMATION THAT WE GATHER?

The team will summarize the information gathered from interviews and focus groups (small groups assembled to identify and discuss key issues in the community) and present it in both written and verbal form to your community at a community forum.

YOUR PARTICIPATION IS VOLUNTARY AND CONFIDENTIAL.

If you agree to participate in this study, please understand that your participation is voluntary (you do not have to do it). Any information that you provide will remain confidential. Your name and address may be collected, but it will not be used in any way in the research study or linked to your responses. It will only be used to invite you to attend the community forum.

Every effort will be taken to protect the identity of the participants in this study. However, there is no guarantee that the information cannot be obtained by legal process or court order. Information such as age and number of years residing in Johnston County may be gathered during the interview. These descriptive characteristics are collected only to help summarize our data. When we report the data, all identifying information will be removed. Your responses and comments will not be linked to you. The only people with access to all data are the members of the student team and the faculty advisors. All notes and audiotapes containing your interview responses will be stored in a locked cabinet at the School of Public Health and will be destroyed in May 2005 when the study is over.

CAN YOU REFUSE OR STOP PARTICIPATION?

Yes. You are free to stop participating at any time. You can refuse to answer any questions. During the interview you may ask that the recording be stopped at any time.

WHO IS IN CHARGE OF THIS PROJECT? HOW CAN I CALL THEM?

This is a student project being conducted under the supervision of our faculty advisor, Eugenia Eng. If you have any questions about this project and/or you wish to withdraw at any time, you may contact graduate student, Katie Emmet, or Eugenia Eng. Their contact information follows:

Katie Emmet (919) 966-5542

UNC School of Public Health

Campus Box 7440, Chapel Hill, NC 27599-7440

Eugenia Eng (919) 966-3909

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Agreement Statement:

By signing this consent form, we agree that we have read and understand the information presented here.

Participant:

I freely give my consent to participate in the Action-Oriented Community Diagnosis.

(your signature and date)

Legal Guardian:

I freely give my consent for _____ to participate in the Action-Oriented Community Diagnosis.

(your signature and date)

(team member signature and date)

Thank you!

Appendix E-3: Focus Group Consent Forms

Focus Group Consent Form for Community/Family Members

Would you like to participate in an AOCD of your community?

WHAT IS AOCD? AOCD means Action-Oriented Community Diagnosis. AOCD is a research assessment designed to understand the cultural, social, economic, and health experiences of individuals living in Johnston County. The purpose is to better understand the experiences of persons with disabilities living in Johnston County and their families.

WHY ARE YOU PARTICIPATING IN AOCD?

You are being asked to participate because we want to gain perspective from individuals with disabilities, family members, other community members, and service providers on Johnston County's strengths and needs regarding services and supports for people with disabilities. Someone in your community identified you as a person who can talk about the views of your community as a whole.

WHAT WILL YOU BE ASKED TO DO?

You will be asked to participate in a 90-minute focus group (small groups assembled to identify and discuss key issues in the community) facilitated by team members from the UNC School of Public Health. There are no wrong answers or bad ideas, just different opinions. If you do not feel comfortable answering a question or do not have an opinion, just let us know. We are interested in your perspective as a community member and/or family member. Your participation is limited to this one focus group, and you will not be contacted for further sessions.

If you agree to participate in the focus group we will record your comments on a piece of paper. Also, with your permission, we would like to tape record the discussion to make sure we do not miss anything. Only members of our group will listen to the tapes. The tapes will be erased after our study is over. You can ask us to turn off the tape recorder at any time. If you decide to participate in this focus group, you will be asked to sign an "informed consent" form. Signing the form means that you understand the purpose of the AOCD project and what you will be asked to do during the project. It also means that you understand that you can stop taking part in the project at any time.

WHAT ARE THE BENEFITS AND RISKS OF MY PARTICIPATION?

You will have the opportunity to share your thoughts about the future of Johnston County. Your participation may help to make things better in your community over time. You will not be paid to participate in this focus group, but refreshments will be provided. There are minimal physical, psychological, or social risks associated with participating in this study. However, one potential risk may arise if you make any negative comments about your community or individuals within the community, and that information is disclosed, your reputation may be affected. We will do the best we can to protect you from this risk by keeping all data in a locked file cabinet at the School of Public Health. In addition, your name will never be attached to anything you say. Also, talking about life issues can sometimes be uncomfortable. Your decision to take part in this study will not influence any of the services you receive or might receive.

WHAT ARE THE COSTS OF TAKING PART IN THIS PROJECT?

The only costs are the time and expense of traveling to and from the focus group and the time spent during the focus group.

WHAT WILL WE DO WITH THE INFORMATION THAT WE GATHER?

The team will summarize the information gathered from interviews and focus groups and present it in both written and verbal form to your community at a community forum.

YOUR PARTICIPATION IS VOLUNTARY AND CONFIDENTIAL.

If you agree to participate in this study, please understand that your participation is voluntary (you do not have to do it). Any information that you provide will remain confidential. Your name and address may be collected, but it will not be used in any way in the research study or linked to your responses, it will only be used to invite you to attend the community forum.

To respect your privacy and confidentiality, and that of other participants, we ask that you not repeat anything that is shared today in this focus group. To ensure confidentiality, you may use a made-up name during the focus group, but please sign your real name on the consent form. Information such as age and number of years residing in Johnston County may be gathered during the focus group. These descriptive characteristics are collected only to help summarize our data. When we report the data, all identifying information will be removed. Your responses and comments will not be linked to you. The only people with access to all data are the members of the student team and the faculty advisors. All notes and audiotapes containing your focus group responses will be stored in a locked cabinet at the School of Public Health and will be destroyed in May 2005 when the study is over.

CAN YOU REFUSE OR STOP PARTICIPATION?

Yes. You are free to stop participating at any time. You can choose not to answer any questions or stop taking part in the focus group at any time. During the focus group you may ask that the recording be stopped at any time.

WHO IS IN CHARGE OF THIS PROJECT? HOW CAN I CALL THEM?

This is a student project being conducted under the supervision of our faculty advisor, Eugenia Eng. If you have any questions about this project and/or you wish to withdraw at any time, you may contact graduate student, Katie Emmet, or Eugenia Eng. Their contact information follows:

Katie Emmet (919) 966-5542	Eugenia Eng (919) 966-3909
UNC School of Public Health	UNC School of Public Health
Campus Box 7440, Chapel Hill, NC 27599-7440	Campus Box 7440, Chapel Hill, NC 27599-7440

This project has been approved by the UNC-CH Public Health Institutional Review Board, Office of Human Research Ethics. If you have questions about your rights as a study participant, or are dissatisfied at any time with any aspect of this study, you may contact -- anonymously, if you wish -- the Public Health Institutional Review Board, Office of Human Research Ethics, University of North Carolina at Chapel Hill, CB # 7400, Chapel Hill, NC 27599-7400, or by phone 919-966-3012. You may call collect.

Agreement Statement:

By signing this consent form, I agree that I have read and understand the information presented here, and I freely give my consent to participate in the Action-Oriented Community Diagnosis. I also agree to keep everything that is shared in the focus group confidential and not share it with anyone outside of this group.

(your signature and date)

(team member signature and date)

Thank you!

Appendix E-3: Focus Group Consent Forms

Focus Group Consent Form for Service Providers

Would you like to participate in an AOCD of your community?

WHAT IS AOCD? AOCD means Action-Oriented Community Diagnosis. AOCD is a research assessment designed to understand the cultural, social, economic, and health experiences of individuals living in Johnston County. The purpose is to better understand the experiences of persons with disabilities living in Johnston County and their families.

WHY ARE YOU PARTICIPATING IN AOCD?

You are being asked to participate because we want to gain perspective from individuals with disabilities, family members, other community members, and service providers on Johnston County's strengths and needs regarding services and supports for people with disabilities. Someone in your community identified you as a person who can talk about the views of your community as a whole.

WHAT WILL YOU BE ASKED TO DO?

You will be asked to participate in a 90-minute focus group (small groups assembled to identify and discuss key issues in the community) facilitated by team members from the UNC School of Public Health. There are no wrong answers or bad ideas, just different opinions. If you do not feel comfortable answering a question or do not have an opinion, just let us know. We are interested in your perspective as a service provider in Johnston County. Your participation is limited to this one focus group, and you will not be contacted for further sessions.

If you agree to participate in the focus group we will record your comments. Also, with your permission, we would like to tape record the discussion to make sure we do not miss anything. Only members of our group will listen to the tapes. The tapes will be erased after our study is over. You can ask us to turn off the tape recorder at any time. If you decide to participate in this focus group, you will be asked to sign an "informed consent" form. Signing the form means that you understand the purpose of the AOCD project and what you will be asked to do during the project. It also means that you understand that you can stop taking part in the project at any time.

WHAT ARE THE BENEFITS AND RISKS OF MY PARTICIPATION?

You will have the opportunity to share your thoughts about the future of Johnston County. Your participation will provide useful information that can be used by Johnston County to plan and improve services available for its residents. You will not be paid to participate in this focus group, but refreshments will be provided. There are minimal physical, psychological, or social risks associated with participating in this study. However one potential risk may arise if you say any bad things about the community or the services you provide in the community, and that information is divulged, you may be at risk for losing your job. Such information could also affect any political career you may choose to pursue. We will do the best we can to protect you from this risk by keeping all data in a locked file cabinet at the School of Public Health. In addition, your name will never be attached to anything you say.

WHAT ARE THE COSTS OF TAKING PART IN THIS PROJECT?

The only costs are the time and expense of traveling to and from the focus group and the time spent during the focus group.

WHAT WILL WE DO WITH THE INFORMATION THAT WE GATHER?

The team will summarize the information gathered from interviews and focus groups and present it in both written and verbal form to your community at a community forum.

YOUR PARTICIPATION IS VOLUNTARY AND CONFIDENTIAL.

If you agree to participate in this study, please understand that your participation is voluntary (you do not have to do it). Any information that you provide will remain confidential. Your name and address may be collected, but it will not be used in any way in the research study or linked to your responses. It will only be used to invite you to attend the community forum. To respect your privacy and confidentiality, and that of other participants, we ask that you not repeat anything that is shared today in this focus group. To ensure confidentiality, you may use a made-up name during the focus group, but please sign your real name on the consent form. Information such as age and number of years residing in Johnston County may be gathered during the focus group. These descriptive characteristics are collected only to help summarize our data. When we report the data, all identifying information will be removed. Your responses and comments will not be linked to you. The only people with access to all data are the members of the student team and the faculty advisors. All notes and audiotapes containing your focus group responses will be stored in a locked cabinet at the School of Public Health and will be destroyed in May 2005 when the study is over.

CAN YOU REFUSE OR STOP PARTICIPATION?

Yes. You are free to stop participating at any time. You can choose not to answer any questions or stop taking part in the focus group at any time. During the focus group you may ask that the recording be stopped at any time.

WHO IS IN CHARGE OF THIS PROJECT? HOW CAN I CALL THEM?

This is a student project being conducted under the supervision of our faculty advisor, Eugenia Eng. If you have any questions about this project and/or you wish to withdraw at any time, you may contact graduate student, Katie Emmet, or Eugenia Eng. Their contact information follows:

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Agreement Statement:

By signing this consent form, I agree that I have read and understand the information presented here, and I freely give my consent to participate in the Action-Oriented Community Diagnosis. I also agree to keep everything that is shared in the focus group confidential and not share it with anyone outside of this group.

(your signature and date)

(team member signature and date)

Thank you!

Appendix E-3: Focus Group Consent Forms

Focus Group Consent Form for Community Member with a Disability Would you like to participate in an AOCD of your community?

WHAT IS AOCD? AOCD means Action-Oriented Community Diagnosis. AOCD is a research assessment designed to understand the cultural, social, economic, and health experiences of individuals living in Johnston County. The purpose is to better understand the experiences of persons with disabilities living in Johnston County and their families.

WHY ARE YOU PARTICIPATING IN AOCD?

You are being asked to participate because we want to gain perspective from individuals with disabilities, family members, other community members, and service providers on Johnston County's strengths and needs regarding services and supports for people with disabilities. Someone in your community identified you as a person who can talk about the views of your community as a whole.

WHAT WILL YOU BE ASKED TO DO?

You will be asked to participate in a 90-minute focus group (small groups assembled to identify and discuss key issues in the community) facilitated by team members from the UNC School of Public Health. There are no wrong answers or bad ideas, just different opinions. If you do not feel comfortable answering a question or do not have an opinion, just let us know. We are interested in your perspective as a community member with a disability. Your participation is limited to this one focus group, and you will not be contacted for further sessions.

If you agree to participate in the focus group we will record your comments on a piece of paper. Also, with your permission, we would like to tape record the discussion to make sure we do not miss anything. Only members of our group will listen to the tapes. The tapes will be erased after our study is over. You can ask us to turn off the tape recorder at any time. If you decide to participate in this focus group, you will be asked to sign an "informed consent" form. Signing the form means that you understand the purpose of the AOCD project and what you will be asked to do during the project. It also means that you understand that you can stop taking part in the project at any time.

WHAT ARE THE BENEFITS AND RISKS OF MY PARTICIPATION?

You will have the opportunity to share your thoughts about the future of Johnston County. Your participation may help to make things better in your community over time. You will not be paid to participate in this focus group, but refreshments will be provided. There are minimal physical, psychological, or social risks associated with participating in this study. However, one potential risk may arise if you make any negative comments about your community or individuals within the community, and that information is disclosed, your reputation may be affected. We will do the best we can to protect you from this risk by keeping all data in a locked file cabinet at the School of Public Health. In addition, your name will never be attached to anything you say. Also, talking about life issues can sometimes be uncomfortable. Your decision to take part in this study will not influence any of the services you receive or might receive.

WHAT ARE THE COSTS OF TAKING PART IN THIS PROJECT?

The only costs are the time and expense of traveling to and from the focus group and the time spent during the focus group.

WHAT WILL WE DO WITH THE INFORMATION THAT WE GATHER?

The team will summarize the information gathered from interviews and focus groups and present it in both written and verbal form to your community at a community forum.

YOUR PARTICIPATION IS VOLUNTARY AND CONFIDENTIAL.

If you agree to participate in this study, please understand that your participation is voluntary (you do not have to do it). Any information that you provide will remain confidential. Though your name and address may be collected, it will not be used in any way in the research study or linked to your responses. It will only be used to invite you to attend the community forum.

To respect your privacy and confidentiality, and that of other participants, we ask that you not repeat anything that is shared today in this focus group. To ensure confidentiality, you may use a made-up name during the focus group, but please sign your real name on the consent form. Information such as age and number of years residing in Johnston County may be gathered during the focus group. These descriptive characteristics are collected only to help summarize our data. When we report the data, all identifying information will be removed. Your responses and comments will not be linked to you. The only people with access to all data are the members of the student team and the faculty advisors. All notes and audiotapes containing your focus group responses will be stored in a locked cabinet at the School of Public Health and will be destroyed in May 2005 when the study is over.

CAN YOU REFUSE OR STOP PARTICIPATION?

Yes. You are free to stop participating at any time. You can choose not to answer any questions or stop taking part in the focus group at any time. During the focus group you may ask that the recording be stopped at any time.

WHO IS IN CHARGE OF THIS PROJECT? HOW CAN I CALL THEM?

This is a student project being conducted under the supervision of our faculty advisor, Eugenia Eng. If you have any questions about this project and/or you wish to withdraw at any time, you may contact graduate student, Katie Emmet, or Eugenia Eng. Their contact information follows:

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Agreement Statement:

By signing this consent form, I agree that I have read and understand the information presented here, and I freely give my consent to participate in the Action-Oriented Community Diagnosis. I also agree to keep everything that is shared in the focus group confidential and not share it with anyone outside of this group.

(your signature and date)

(team member signature and date)

Thank you!

Appendix E-3: Focus Group Consent Forms

Focus Group Consent Form for Community Member with a Disability Would you like to participate in an AOCD of your community?

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WHAT WILL YOU BE ASKED TO DO?

You will be asked to participate in a 90-minute focus group (small groups assembled to identify and discuss key issues in the community) facilitated by team members from the UNC School of Public Health. There are no wrong answers or bad ideas, just different opinions. If you do not feel comfortable answering a question or do not have an opinion, just let us know. We are interested in your perspective as a community member with a disability. Your participation is limited to this one focus group, and you will not be contacted for further sessions.

If you agree to participate in the focus group we will record your comments on a piece of paper. Also, with your permission, we would like to tape record the discussion to make sure we do not miss anything. Only members of our group will listen to the tapes. The tapes will be erased after our study is over. You can ask us to turn off the tape recorder at any time. If you decide to participate in this focus group, you will be asked to sign an "informed consent" form. Signing the form means that you understand the purpose of the AOCD project and what you will be asked to do during the project. It also means that you understand that you can stop taking part in the project at any time.

WHAT ARE THE BENEFITS AND RISKS OF YOUR PARTICIPATION?

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WHAT ARE THE COSTS OF TAKING PART IN THIS PROJECT?

The only costs are the time and expense of traveling to and from the focus group and the time spent during the focus group.

WHAT WILL WE DO WITH THE INFORMATION THAT WE GATHER?

The team will summarize the information gathered from interviews and focus groups and present it in both written and verbal form to your community at a community forum.

YOUR PARTICIPATION IS VOLUNTARY AND CONFIDENTIAL.

If you agree to participate in this study, please understand that your participation is voluntary (you do not have to do it). Any information that you provide will remain confidential. Though your name and address may be collected, it will not be used in any way in the research study or linked to your responses. It will only be used to invite you to attend the community forum.

To respect your privacy and confidentiality, and that of other participants, we ask that you not repeat anything that is shared today in this focus group. To ensure confidentiality, you may use a made-up name during the focus group, but please sign your real name on the consent form. Information such as age and number of years residing in Johnston County may be gathered during the focus group. These descriptive characteristics are collected only to help summarize our data. When we report the data, all identifying information will be removed. Your responses and comments will not be linked to you. The only people with access to all data are the members of the student team and the faculty advisors. All notes and audiotapes containing your focus group responses will be stored in a locked cabinet at the School of Public Health and will be destroyed in May 2005 when the study is over.

CAN YOU REFUSE OR STOP PARTICIPATION?

Yes. You are free to stop participating at any time. You can choose not to answer any questions or stop taking part in the focus group at any time. During the focus group you may ask that the recording be stopped at any time.

WHO IS IN CHARGE OF THIS PROJECT? HOW CAN I CALL THEM?

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Agreement Statement:

By signing this consent form, we agree that we have read and understand the information presented here.

Participant:

I freely give my consent to participate in the Action-Oriented Community Diagnosis.

(your signature and date)

Legal Guardian:

I freely give my consent for _____ to participate in the Action-Oriented Community Diagnosis.

(your signature and date)

(team member signature and date)

Thank you!

Appendix E-4: Recruitment Consent Form

Recruitment Consent Form

Purpose of this form:

This form provides guidelines for service providers, community members (with and without disabilities), and family members and legal guardians of persons with disabilities to receive permission to release name and contact information of potential interviewees and focus group participants to the Johnston County Community Diagnosis research team. If an individual agrees to be contacted by the Community Diagnosis research team, more information about the study will be provided and the individual will have the opportunity to decide if he or she wishes to participate. Recruiters will not learn whether or not an individual decides to participate or not. In the case of individuals recruited through service providers, care will be taken to ensure the individual is aware that services he or she may utilize will not be affected in any way. This information will only be released to the Community Diagnosis research team. This guide will be provided to anyone who will be involved in recruiting participants for this project including service providers, community members (with and without disabilities), and family members and legal guardians of persons with disabilities. This script will be given or read to potential study participants.

Script:

A team of students from the UNC School of Public Health is conducting a study of the cultural, social, economic, and health experiences of the Johnston County community and the unique experiences of persons with disabilities living in this community. They would be interested in contacting you to participate in an interview or focus group for their study. If you agree to be contacted by the team, you will be given more information about the study and have the opportunity to decide if you wish to participate in it or not. I will not know whether you decide to participate or not. Regardless of your decision, any services you may utilize will not be affected in any way. If you have any questions about the study, you can contact Katie Emmet, a graduate student at UNC, or the faculty advisor Eugenia Eng, DrPH.

Katie Emmet (919) 966-5542

Eugenia Eng (919) 966-3909

Toll-free Number: (866) 610-8273

UNC School of Public Health

UNC School of Public Health

Dept of Health Behavior and Health Education

Dept of Health Behavior and Health Education

Campus Box 7440

Campus Box 7440


Chapel Hill, NC 27599-7440

Chapel Hill, NC 27599-7440

May I have permission to give your name and contact information to them?

Appendix E-5: IRB Approval Letter



TO: Katie Emmet
DEPARTMENT: Health Behavior and Health Education
ADDRESS: CB# 7440
DATE: 11/15/2004
FROM: 
Andrea K. Biddle, PhD, Chair
Public Health IRB, Office of Human Research Ethics

IRB NUMBER: 04-2424
APPROVAL PERIOD: 11/15/2004 through 11/14/2005
TITLE: Action-Oriented Community Diagnosis of Johnston County,
North Carolina
SUBJECT: Expedited Protocol Approval Notice--New Protocol

Your research project has been reviewed under an expedited procedure because it involves only minimal risk to human subjects. This project is approved for human subjects research, and is valid through the expiration date above.

NOTE:

(1) This Committee complies with the requirements found in Part 56 of the 21 Code of Federal regulations and Part 46 of the 45 Code of Federal regulations. Federalwide Assurance Number: FWA-4801, IRB No. IRB540.

(2) Re-review of this proposal is necessary if (a) any significant alterations or additions to the proposal are made, OR (b) you wish to continue research beyond the expiration date.

The University of North Carolina
at Chapel Hill
Campus Box 7400
Chapel Hill, NC 27599-7400
Phone: 919.966.7676
Fax: 919.966.6380
www.sph.unc.edu

Appendix F-1: Interview Guides

Service Provider Interview Guide

Introduction: Hello, my name is _____. I'm going to be leading our interview today. This is _____, who will be taking notes and helping me during our discussion. We'll be here about 60 minutes to talk to you about the role your group or organization has in the Johnston County community, and about your opinions concerning the strengths of Johnston County and the challenges it faces. We are especially interested in learning about the experiences of persons with disabilities living in Johnston County. Your insights and opinions on this subject are important, so please say what's on your mind and what you think. There are no right or wrong answers.

First, I am going to ask you a few questions about Johnston County in general, and then I have some questions about life in Johnston County specifically for persons with disabilities.

Description of Service Provider and Agency

1. Tell me about your work.
 - *What agency?*
 - *Where is it located?*
 - *What is your role? Probe: job title*
2. How long have you worked at this agency? Why did you choose to work here?
3. Tell us about your agency in general. What services does your agency provide?
4. Describe the most frequent users of your services? *Probe: geographical information, SES, ethnicity, etc.*
5. What barriers do people face when trying to access your agency's services? Why?
6. Are there groups that tend to be difficult for your agency to reach? *Probe: geographic, transportation, cultural, language*

Roles and Responsibilities of Service Providers

7. What steps do you take to facilitate access to your agency's services?
8. If someone has questions about services for persons with disabilities, whom can they talk to at your agency?
 - *Is that person your ADA Coordinator/do you have an ADA coordinator?*
 - *If yes, how would I contact that person?*
9. What other agencies provide services to the residents of the communities you serve?
 - *What kinds of services do they provide?*

Assets Found in the Community

10. How would you describe Johnston County? *Probe: Would you define it as a community?*
11. How would you describe the community for people with disabilities?
12. What are some of the best things about Johnston County for people with disabilities?
13. What do you think are the major challenges facing persons with disabilities in your community?
Probe: healthcare, accessibility, services, discrimination
14. Which challenges do you feel are the **most** important to address? *Probe: Why?*
15. If you or someone in your family [had or has] a disability, how [would or do] you feel about living in Johnston County?
16. If you had the power to change things in Johnston County, what would you change? *Probe: What services would you offer? What programs would you modify or cancel?*
 - *What about for people with disabilities?*

Recommended Individuals to Interview

17. We are hoping to interview several people in the community who know what is going on in the community and might be able to speak on behalf of the residents of Johnston County. Would you like to recommend someone else to be interviewed? (*service providers, residents*)
- a. *Describe the specific person or organization*
 - b. *Why do you think their opinions and views would be helpful for us to hear?*
 - c. *Are you willing to get permission for us to contact them?*

Recommendations for Community Forum

18. We are going to be conducting a community forum in April where we will share the information we have gathered with the community. The forum is designed to bring people in Johnston County together to talk about issues for persons with disabilities. We will be sharing some of the things we have learned from our interviews and hope this will be an opportunity for community members, family members, persons with disabilities, and service providers to come together, pool resources, and brainstorm possible solutions. Would you be interested in being involved with this event?

We are specifically looking for individuals who would be willing to serve on a community advisory board. The purpose of the board will be to plan a forum that community members will want to attend and to follow-up on potential ideas and suggestions that are generated as a result of the forum. We anticipate that we will probably have 3-4 planning meetings in March and April prior to the actual event.

19. Do you have any ideas regarding how to get people to attend? *Probe: time, place, publicity, door prizes, special activities that would attract people to this meeting*
20. Who else do you think should help us coordinate this forum?

Additional Information

22. Is there anything else you would like to share about the Johnston County community?
23. Questions from note-taker?

Thank you again for your participation!

Appendix F-1: Interview Guides

Family Member Interview Guide

Introduction: Hello, my name is _____. I'm going to be leading our interview today. This is _____, who will be taking notes and helping me during our discussion. We will be here about 60 minutes to talk to you about living in Johnston County and your opinions concerning the strengths of Johnston County and the challenges it faces. We are especially interested in learning about your experiences as a family member of a person living with disabilities in Johnston County. Your insights and opinions on this subject are important, so please say what's on your mind and what you think. There are no right or wrong answers.

First I am going to ask you a few questions about Johnston County in general, and then I have some questions about life in Johnston County specifically for persons with disabilities.

Life in Johnston County

1. Do you currently live and work in Johnston County? *If yes, where?*
2. Describe life in Johnston County.
 - *Housing*
 - *Employment*
 - *Schools*
 - *Transportation/travel time*
 - *Recreation activities*
 - *Religion*
 - *Healthcare*
3. How do you feel about the recent growth in Johnston County?
4. What do you think are some of the best things about Johnston County?
5. What do you think are some of the challenges facing Johnston County?

People with Disabilities: Strengths and Challenges

6. What about for people with disabilities—what do you think life is like for them and their families?
 - *Housing, employment, schools, transportation/travel time, recreation activities, healthcare*
7. What do you think are some of the best things about life in Johnston County for people with disabilities and their families?
8. What do you think are the challenges facing persons with disabilities in Johnston County and their families? *Probe: accessibility, services, discrimination*
9. How have these challenges affected you and your family personally?
10. What strengths/resources does Johnston County have to help families deal with these challenges?
11. How do people support one another in Johnston County?

Programs and Services

12. What kinds of programs/services are offered in Johnston County? How are services made available to persons with disabilities and their families? *Probe: education, recreation, health services, etc.*
13. How do you feel about the services available for persons with disabilities? *Probe: strengths, challenges, etc.*
14. To what extent are families involved or included in services for persons with disabilities?

General Community

15. If someone were to ask you if Johnston County is a good place to live for people with disabilities and their families, how would you respond?

Demographic/Background Information

Just real quick, if you don't mind, we have a few personal background questions.

16. How long have you lived in Johnston County?
17. How old are you? *Probe: approximately*
18. would you describe your ethnicity?

Recommended Individuals to Interview

19. Is there anyone else in the community who you think it is important for us to talk to about these issues? *Probe: members of other families, service providers, or other residents*

Describe the specific person or organization.

Why do you think their opinions and views would be helpful for us to hear?

Are you willing to get permission for us to contact them?

Recommendations for Community Forum

20. We are going to be conducting a community forum in April where we will share the information we have gathered with the community. The forum is designed to bring people in Johnston County together to talk about issues for persons with disabilities. We will be sharing some of the things we have learned from our interviews and hope this will be an opportunity for community members, family members, persons with disabilities, and service providers to come together, pool resources, and brainstorm possible solutions. Would you be interested in being involved with this event?

We are specifically looking for individuals who would be willing to serve on a community advisory board. The purpose of the board will be to plan a forum that community members will want to attend and to follow-up on potential ideas and suggestions that are generated as a result of the forum. We anticipate that we will probably have 3-4 planning meetings in March and April prior to the actual event.

21. Do you have any ideas regarding how to get people to attend? *Probe: time, place, publicity, door prizes, special activities that would attract people to this meeting*
22. Who else do you think should help us coordinate this forum?

Additional Information

23. Is there anything else you'd like to tell us about your experiences as a family member of a person living with disabilities in Johnston County?
24. Questions from the note-taker?

Thank you again for your participation!

Appendix F-1: Interview Guides

Community Members (with and without disabilities) Interview Guide

Introduction: Hello, my name is _____. I'm going to be leading our interview today. This is _____, who will be taking notes and helping me during our discussion. We will be here about 60 minutes to talk to you about living in Johnston County and your opinions concerning the strengths of Johnston County and the challenges it faces. We are especially interested in learning about the experiences of persons with disabilities living in Johnston County. Your insights and opinions on these subjects are important, so please say what's on your mind and what you think. There are no right or wrong answers.

First I am going to ask you a few questions about Johnston County in general, and then I have some questions about life in Johnston County specifically for persons with disabilities.

Life in Johnston County

1. Describe life in Johnston County.
 - *Housing*
 - *Employment*
 - *Transportation/travel time*
 - *Schools*
 - *Recreation activities*
 - *Religion*
 - *Healthcare*
2. How do you feel about the recent growth in Johnston County?
3. What do you think are some of the best things about Johnston County?
4. What do you think are some of the challenges facing Johnston County?

People with Disabilities: Strengths and Challenges

5. What about for people with disabilities—what is life like for them?
 - *Housing, employment, transportation/travel time, schools, recreation activities, healthcare*
6. What are some of the best things about Johnston County for people with disabilities? *Probe: strengths, resources in the community*
7. What are the challenges facing people with disabilities in Johnston County?
 - *Accessibility, services, discrimination*
8. How do you think Johnston County could better serve people with disabilities?
 - *If you were in charge, what would you change?*
9. How do people support one another in Johnston County?

Services and Businesses

10. What kinds of programs/services are offered to people with disabilities in Johnston County? *Probe: education, recreation, health services, etc*
11. What services and businesses do you use most frequently in the community? *Services include: social services, medical, police, DMV, government offices etc.*
 - *Do those services come to you or do you go to them? How far?*
12. Can you describe your experience with service providers in the community? *Probe: attitude, behavior, how do they help you? Meet your needs?*
13. What services and businesses do you avoid using in the community? *To clarify: Too far? Heard bad things?*
 - *Why don't you use these services?*

General Community

14. If someone were to ask you if Johnston County is a good place to live for people with disabilities, how would you respond?

***Demographic/background info**

Just real quick, if you don't mind, we have a few personal background questions.

15. Where do you live in Johnston County?
16. How long have you lived in Johnston County?
17. How old are you? *Probe: approximately*
18. How would you describe your ethnicity?

Recommended Individuals to Interview

19. Is there anyone else in the community who you think it is important for us to talk to about these issues? *Probe: service providers, residents*
 - *Describe the specific person or organization*
 - *Why do you think their opinions and views would be helpful for us to hear?*
 - *Are you willing to get permission for us to contact them?*

Recommendations for Community Forum

20. We are going to be conducting a community forum in April where we will share the information we have gathered with the community. The forum is designed to bring people in Johnston County together to talk about issues for persons with disabilities. We will be sharing some of the things we have learned from our interviews and hope this will be an opportunity for community members, family members, persons with disabilities, and service providers to come together, pool resources, and brainstorm possible solutions. Would you be interested in being involved with this event?

We are specifically looking for individuals who would be willing to serve on a community advisory board. The purpose of the board will be to plan a forum that community members will want to attend and to follow-up on potential ideas and suggestions that are generated as a result of the forum. We anticipate that we will probably have 3-4 planning meetings in March and April prior to the actual event.

20. Do you have any ideas regarding how to get people to attend? *Probe: time, place, publicity, door prizes, special activities that would attract people to this meeting*
21. Who else do you think should help us coordinate this forum?

Additional Information

22. Is there anything else you want to tell us about the Johnston County community?
23. Questions from note-taker?

Thank you again for your participation!

Appendix F-2: Focus Group Guides

Family Members Focus Group Guide

Introduction: Hello, my name is _____ I'm going to be leading our focus group today. This is _____, who will be taking notes and helping me during our discussion. We will be here about 90 minutes to talk to you about living in Johnston County and your opinions concerning the strengths of Johnston County and the challenges it faces. We are especially interested in learning about your experiences of persons with disabilities and their families in Johnston County. Your insights and opinions on this subject are important, so please say what's on your mind and what you think.

We ask that you do not discuss what you have heard in this room after the focus group is over. Please remember that you do not have to answer any questions that you are uncomfortable with and that there are no right or wrong answers. At this time, we will hand out a focus group confidentiality statement. If you agree with the statement, please sign the form. First I am going to ask you a few questions about Johnston County in general, and then I have some questions about life in Johnston County specifically for persons with disabilities.

Life in Johnston County

Describe life in Johnston County.

Housing

Employment

Schools

Transportation/travel time

Recreation activities

Religion

Healthcare

1. How do you feel about the recent growth in Johnston County?
2. What do you think are some of the best things about Johnston County?
3. What do you think are the challenges facing Johnston County?

People with Disabilities: Strengths and Challenges

4. What about for people with disabilities—what do you think life is like for them and their families?
 - *Housing, employment, schools, transportation/travel time, recreation activities, healthcare, religion*
5. What do you think are some of the best things about life in Johnston County for people with disabilities and their families?
6. What do you think are the challenges facing persons with disabilities in Johnston County and their families? *Probe: healthcare, accessibility, services, discrimination*
7. How have these challenges affected you and your family personally?
8. What strengths/resources does Johnston County have to help families deal with these challenges?
9. How do people support one another in Johnston County?

Programs and Services

10. What kinds of programs/services are offered in Johnston County? How are services made available to persons with disabilities and their families? *Probe: education, medical, recreation*
11. How do you feel about the services available for persons with disabilities? *Probe: strengths, challenges, etc.*
12. To what extent are families involved or included in services for persons with disabilities?

General Community

13. If someone were to ask you if Johnston County is a good place to live for people with disabilities and their families, how would you respond?

Recommended Individuals to Interview

14. Is there anyone else in the community who you think it is important for us to talk to about these issues? *Probe: members of other families, other residents, or service providers*
If you have someone in mind, would you mind staying for a few minutes after the focus group so that we can find out more information?

Recommendations for Community Forum

15. We are going to be conducting a community forum in April where we will share the information we have gathered with the community. The forum is designed to bring people in Johnston County together to talk about issues for persons with disabilities. We will be sharing some of the things we have learned from our interviews and hope this will be an opportunity for community members, family members, persons with disabilities, and service providers to come together, pool resources, and brainstorm possible solutions. Would you be interested in being involved with this event?
 - a. *If you are interested, would you mind staying for a few minutes after the focus group so that we can find out more information?*
17. Do you have any ideas regarding how to get people to attend? *Probe: time, place, publicity, door prizes, special activities that would attract people to this meeting*

Additional Information

16. Is there anything else you'd like to tell us about your experiences as a family member of a person living with disabilities in Johnston County?
17. Questions from the note-taker?

Thank you again for your participation!

Appendix F-2: Focus Group Guides

Service Providers Focus Group Guide

Introduction:

Hello, my name is _____ I'm going to be leading our focus group today. This is _____, who will be taking notes and helping me during our discussion. We will be here about 60 minutes to talk to you about living in Johnston County and your opinions concerning the strengths of Johnston County and the challenges it faces. We are especially interested in learning about the experiences of persons with disabilities living in Johnston County. Your insights and opinions on this subject are important, so please say what's on your mind and what you think. We ask that you do not discuss what you have heard in this room after the focus group is over. You do not have to answer any questions that you are uncomfortable with. There are no right or wrong answers.

We ask that you do not discuss what you have heard in this room after the focus group is over. Please remember that you do not have to answer any questions that you are uncomfortable with and that there are no right or wrong answers. At this time, we will hand out a focus group confidentiality statement. If you agree with the statement, please sign the form.

1. Let's go around the room and please each of you tell us about your agency and what services it provides. How would you describe the people who utilize your services?
2. What barriers do people face when trying to access your agencies' services? Why? Are there groups that tend to be difficult for your agency to reach? *Probe: geographic, transportation, cultural, language*
3. What steps do you take to facilitate access to these services?
4. Do you know of other agencies provide similar services? If so, what are they?
5. How would you describe Johnston County? *Probe: Would you define it as a community?*
6. How long have you lived in Johnston County?
7. How do you feel about the recent growth in Johnston County?
8. What would you say are the strengths of the communities you serve?
9. What do you think are the major issues facing persons with disabilities in your community? *Probe: Accessibility, Services, Discrimination*
10. What are the implications of these issues?
11. What services does your organization provide to address these issues? *Probe: Does your agency have an ADA Coordinator? If someone has questions about services for persons with disabilities, with whom can they talk?*
12. If you were in charge of community services, what would you do? What if you were in charge of services for persons with disabilities? How would you ensure that persons with disabilities have full access? *Probe: What services would you offer? What programs would you change or cancel?*
13. Have I/we forgotten anything? Is there anything else you would like to say?
14. We are going to be conducting a community meeting where we will present our findings and discuss them with the community. Do you have any suggestions? *Probe: place, day of the week, time of day, format, who to invite, how to publicize, who should serve on planning group.*

Thank you again for your participation.

Appendix F-2: Focus Group Guides

Community Members (with/without disabilities) Focus Group Guide

Introduction:

Hello, my name is _____. I'm going to be leading our focus group today. This is _____, who will be taking notes and helping me during our discussion. We will be here about 90 minutes to talk with you about living in Johnston County and your opinions concerning the strengths of Johnston County and the challenges it faces. We are especially interested in learning about the experiences of people with disabilities living in Johnston County. Your insights and opinions on this subject are important, so please say what's on your mind and what you think. We have given you a form that explains our project and the reason that we are here. It also explains what we are going to do today. I am going to read it and you can follow along. If you understand what is going to happen during our discussion today and want to participate in it, then we ask that you sign the form.

We ask that you do not discuss what you have heard in this room after the focus group is over. Please remember that you do not have to answer any questions that you are uncomfortable with and that there are no right or wrong answers. At this time, we will hand out a focus group confidentiality statement. It says that you will not repeat or discuss what you hear today with anyone outside of this room. If you agree not to repeat what you hear, please sign the form.

GROUND RULES:

We've got a lot to cover, so we will all need to do a few things to get our jobs done:

- Please talk one at a time and in a voice at least as loud as mine.
- Please do not talk while others are talking.
- Because we have a lot to cover, you may be interrupted at some point so that we can keep moving and avoid running out of time.

Icebreaker: What is one thing that you like about being a student at Johnston Community College?

Life in Johnston County for People with Disabilities: Strengths and Challenges

1. What is life like in Johnston County?
 - Where do you live? (*Probes: with parents? On your own? Apartments? Houses?*)
 - Do you have a job? If yes: Tell me about your job. (*Probes: Where? Do you like it? What do you do there? How do your employers/boss treat you? How do your co-workers treat you? How do you get there? How long have you worked there?*)
 - How do you get from place to place? (*Probes: Drive? Family members? Friends? JCATS?*)
 - Before coming to JCC, did you go to school in Johnston County? Tell me about what school was like here. (*Probes: type of classroom/classes, teacher, treatment by teacher and other kids, what kind of things did you learn*)
 - Tell me about JCC. Probe: What do you learn/do here?
 - What do you do in Johnston County for fun? (*exercise, movies, with friends, on weekends, entertainment, shopping*)
 - Where are these places, how do you get there, who do you go with?
2. What is something you like about living in Johnston County?

3. When you need help with something (*such as reading a form, finding something, getting somewhere, cooking dinner*)—who helps you?
4. What things are hard about of living in Johnston County?
 - *Are there things you need help with but can't find the help? Are there services you think Johnston County needs to have but doesn't?*
 - *How are you treated by people you meet or that you do not know well?*
5. Would you change anything about Johnston County so that it could better serve you? If you were in charge, what would you change?

Services and Businesses

6. Where do you go to the doctor – Johnston County or somewhere else? Which hospital do you go to if you have an emergency? How do you get there?
7. Do you go (have you gone) to JCI? If yes: What kinds of activities do/did you do at JCI? Did they help you get a job? If so, what kinds of jobs? Do/did you like it? Why or why not? How do/did you get there?
8. Do you go/have you gone to Special Olympics? If yes: What do/did you do at Special Olympics? Do/did you like it? Why or why not? How do/did you get there?
9. Do you ride/have you rode the JCATS bus? When? Where does/did take you? If no or not taking JCATS now: why not?
10. Do you use/have you used Vocational Rehabilitation? If yes: What kinds of activities do/did you do at Voc Rehab? Do/did they help you get a job? Do/did you like it? Why or why not? How do/did you get there?
11. What other places do you go to for help in Johnston County? (Probes: help finding a job, help paying bills, help learning to drive, etc).

General Community

12. If someone were to ask you if Johnston County is a good place to live for people with disabilities, how would you respond?

Recommendations for Community Forum

13. We are going to be conducting a community meeting in April where we will share the information we have gathered with the community. The meeting is designed to bring people in Johnston County together to talk about issues for persons with disabilities. We will be sharing some of the things we have learned from our interviews and hope this will be an opportunity for community members, family members, persons with disabilities, and service providers to come together, pool resources, and brainstorm possible solutions. Would you be interested in being involved with this event?
 - *If you are interested in being involved, would you mind staying for a few minutes after the focus group so that we can find out more information?*
11. Do you have any ideas regarding how to get people to come? *Probe: time, place, publicity, door prizes, special activities that would attract people to this meeting*

Additional Information

12. Is there anything else you'd like to tell us about your experiences as a community member or as a person living with disabilities in Johnston County?
13. Questions from the note-taker?

Thank you again for your participation!

Appendix F-3: Focus Group Confidentiality Statement

Action-Oriented Community Diagnosis: Confidentiality Statement

Interview

Focus Group

You are being asked to sign the following statement because you will be attending a focus group or interview in order to provide support for one of more of the individual participants.

Confidentiality Statement:

I understand that I will be attending this group as an observer not as a participant. I agree to protect the confidentiality of all participants by not repeating anything that is stated today outside of the context of this interview or focus group.

(Please sign and date)

Appendix F-4: Project Interest Form

Project Interest Form

We hope that you will continue to be a part of our AOCD!

Are you interested in becoming involved with the Johnston County Community Forum planning committee?

Would you like to receive information about AOCD activities in Johnston County?

If so, please share your contact information below.

This information will not be connected to any of the information that you have just shared with us in the focus group or interview. It will only be used to let you know more about the AOCD project and to invite you to attend the Community Forum.

Contact Information

Name:	
Address:	
City, State, Zip Code	
Telephone Number:	
Cell Phone Number:	
E-mail Address:	
Best way/time to reach you:	

Appendix F-5: Demographic Information for Focus Groups Form

FOCUS GROUP BACKGROUND INFORMATION SHEET

14. How long have you lived in Johnston County? _____ (years)

15. Do you currently work in Johnston County?

Yes No

16. How old are you? _____

4. How would you describe your ethnicity? _____