

**Raleigh**  
**Wake County**

**An Action-Oriented Community Diagnosis**  
**For people living with disabilities in Raleigh, NC**

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Maureen Boland

Karen Isaacs

Jill Kunkel

Ayana Mangum

Darcie Mersereau

Allison Myers

Preceptors:

Fred Johnson and Rene Cummins, Universal Disability Advocates and Center  
for Independent Living

Pam Dickens, MPH and Karen Luken, MSRA, CTRS, North Carolina Office on  
Disability and Health

Instructors: Geni Eng, DrPH and Karen Moore, MPH

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## **Executive Summary**

Universal Disability Advocates (UDA) is a grassroots, nonprofit organization in Raleigh, N.C. that advocates for people of all ages and abilities in the community. Through a partnership with the North Carolina Office on Disability and Health, UDA invited a team of six students from the UNC School of Public Health in Chapel Hill, NC to conduct an Action-Oriented Community Diagnosis (AOCD) of people living with disabilities in Raleigh. Two UDA members and two employees of the NC Office on Disability and Health agreed to serve as preceptors and mentors for the project and as liaisons between the students and the community. The team first entered the community in October 2003 and the AOCD process was completed following a community forum held in April 2004.

The goal of an Action Oriented Community Diagnosis (AOCD) is to gather, analyze, and summarize the perspectives of community members and service providers in a community for the purpose of creating a complete vision of the community's strengths, challenges, and existing resources on which to build. The AOCD process is designed to culminate in a Community Forum where all community stakeholders come together to create action steps to improve existing situations.

The team in Raleigh began the AOCD process by examining secondary data and attending community meetings and events. The team then conducted 32 interviews and 2 focus groups with service providers, individuals with disabilities, and family members of people with disabilities in Raleigh, and identified recurrent themes raised by interviewees. Following a thorough review of all interview transcripts, the team identified the most frequently recurring issues and strengths (called domains) raised by interviewees. The AOCD team then worked with a planning group of

community members and service providers to prioritize the recurrent domains.

The most important and changeable issues identified by people with disabilities in Raleigh included: the accessibility and affordability of housing and Raleigh; issues of public transportation in Raleigh, the Raleigh built environment, specifically, the accessibility of sidewalks, parking lots and buildings; community awareness in Raleigh and communication with people with disabilities; the unemployment and underemployment of people with disabilities in Raleigh; and the challenges around obtaining services in Raleigh. Each of these domains was the topic of a small group discussion at the Raleigh Community Forum.

The Raleigh Community Forum was held on Monday April 19<sup>th</sup> from 6:00 to 8:30 pm at the Hudson Memorial Presbyterian Church on Six Forks Road in Raleigh. Twenty-five community members and service providers attended the forum. After opening remarks, a brief overview of the methodology of the AOCD process and a detailed description of the prioritized issues for discussion, forum attendees divided into small groups. Small group discussions surrounding each domain led to the generation and prioritization of action steps for the future.

Action steps resulting from the small group discussion on the accessibility and affordability of housing in Raleigh included: to attend and speak at at least one builders convention to raise awareness about the needs of people living with disabilities and access to affordable, accessible housing; to raise awareness among the general public through publicity and collaborations with existing organizations like Universal Disability Advocates, The Raleigh Mayor's Committee, Center for Independent Living, and the Center for Universal Design at North Carolina State University; to include housing information on an existing disability advocacy website now in a design phase; and, to, in the long-term, build a visitable housing complex in

accordance with the principles of universal design.

Following a discussion on the Raleigh built environment, specifically, the accessibility of sidewalks, parking lots, and buildings, an action step was to form an email group that will arrive at action steps involving collaboration with other organizations.

Resulting from a discussion on community awareness in Raleigh and communication issues with health care providers, action steps were to: attend existing community activities, such as health fairs, to increase awareness about this uses; to create a “tips for consumers” brochure focusing on how to advocate for ones’ own health needs; and to continue providing continuing education courses for health care professionals regarding communication with people with disabilities.

Action steps resulting from the small group discussion on the unemployment and underemployment of people with disabilities in Raleigh were to: advocate at the state and federal levels by contacting legislators and the governor to ask: Where do people with disabilities fit into your action plans? And is there an action plan for employment for people with disabilities?; to educate the community through existing organizations, to register to vote, and to learn how to effectively advocate for equal employment; and, to educate the community about taking legal action through the Americans with Disabilities Act when necessary.

As a discussion of issues of public transportation in Raleigh did not occur during the community forum, no action steps were created.

In addition to bringing together Raleigh community members and service providers in communication about the future, the AOCD team involved in this project was particularly



interested in the influence of the Americans with Disabilities Act on the presence and functions of community among adults living with disabilities in Raleigh, N.C. Through their research, AOCD team members identified dramatically different views on the existence of a Raleigh community of people with disabilities. This document, which compiles information collected through interviews, secondary data sources, and observations of team members, is written with the understanding that the definition of “community of people living with disabilities” used by the team is meaningful and a truth to some, while not believed to exist nor advocated for by others. The definition of a cross-disability community is considered by some to be the critical foundation for continued efforts to secure rights for people living with disabilities. For others, defining people with disabilities as a community is perceived as furthering the historical segregation of this group from the rest of society. For still others, community is defined within the boundaries of one’s own disability and/or geographical or relational factors.

This AOCD document is intended to serve as a resource to the people of Raleigh. The document is organized into six sections: an Introduction to the Project, Findings from Secondary Data, Results, Community Forum, Methodology, and Conclusions and Next Steps. The team presents this document in the hope that it will contribute to the existing body of knowledge supporting and advancing people living with disabilities in Raleigh, North Carolina. It has been the team’s privilege to learn from so many people working to make Raleigh a more inclusive community for people with disabilities, and the team hopes the action steps for change generated by the community during this project will compliment existing work or serve as a catalyst for new action.



## **Introduction to the Project**

The Americans with Disabilities Act was signed into law by President George H.W. Bush on July 26, 1990. The law provided "a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities"(1). The ADA required that employers, service providers, and public facilities "must attempt to make reasonable accommodations for the physical and mental limitations of individuals with disabilities"(1).

While not the first disability rights legislation to be passed (2), the ADA, with its broad scope and reach, planted the seeds of a transition in the consciousness of American society. The adoption of this public policy affirmed the equal rights of people with disabilities and provided a means for recourse when those rights were violated (2). It also galvanized the disability rights movement and provided a vehicle for cross-disability collaboration and advocacy (3).

According to the ADA, a person living with a disability is defined as someone who, "...has a physical or mental impairment that substantially limits one or more of the major life activities including walking, seeing, hearing, speaking, breathing, learning, and working; has a record of such an impairment; or is regarded as having such an impairment"(4). This broad definition lends itself to the inclusion of a population that consequently makes up the largest minority group in the United States. According to the 2000 Census, 49.7 million people in the U.S., or nearly one in five persons, were living with a disability (5). This group includes people who are born with disabilities or who develop them later in life (e.g. arthritis), who have progressive disabilities, or disabilities that, like temporary paralysis, can disappear altogether. Some disabilities are visually apparent while others are completely hidden; some have no effect on physical or mental capability but may be perceived as disabilities and still lead to discrimination. Coupled with a range in severity of disability and history of rights and access to

resources, the experience of people living with disabilities is extraordinarily varied (6).

The AOCD team involved in this project was particularly interested in the ADA's influence on the presence and functions of community among adults living with disabilities in Raleigh, N.C. Through their research, AOCD team members identified dramatically different views on the existence of a Raleigh community of people living with disabilities. These different views are driven largely by a wide range of life experiences among individuals with disabilities, such as differential access to resources by disability, differing experience with discrimination based on one's disability, and the timing of acquisition and nature of disability.

This document, which compiles information collected through interviews, secondary data sources, and observations of team members, is written with the understanding that the definition of "community of people living with disabilities" used by the team is meaningful and a truth to some, while not believed to exist nor advocated for by others. The definition of a cross-disability community is considered by some to be the critical foundation for continued efforts to secure rights for people living with disabilities. For others, defining people with disabilities as a community is perceived as furthering the historical segregation of this group from the rest of society. For still others, community is defined within the boundaries of one's own disability and/or geographical or relational factors. With this in mind, the team began its efforts by consulting secondary data sources in order to understand the context in which people with disabilities in Raleigh lead their lives.

## **Findings from Secondary Data**

### **Brief History and Profile of Raleigh, North Carolina**

Raleigh, North Carolina was chartered as the state capital in 1792. With state government rather than business enterprise as its primary focus, Raleigh grew slowly and maintained a small, sleepy town feel for much of its early history (7). The early 1900's saw Raleigh develop into a retail and entertainment center for eastern North Carolina, with Fayetteville and East Hargett Streets offering shopping, live performances, and motion pictures (7). Raleigh also developed as an educational center and was the home of some of the earliest colleges for women and African-Americans (7). In 1959, however, big business came to Raleigh when a state initiative created Research Triangle Park (see below) and catapulted Raleigh into its most rapid period of growth, transforming it into one of the fastest growing cities in the United States (8).

Raleigh is the largest of 12 municipalities in Wake County and accounts for 44% of the county's 627,846 residents (9). According to the 2000 Census, Raleigh's population is 276,093, of whom 63% are white, 28% are African-American, 3% are Asian-American, and 7% are other/mixed races, of which 7% are of Hispanic ethnicity (10). Raleigh is dominated by working-aged adults, with 71% of its residents between the ages of 18 and 64, 21% under age 18, and 8% 65 years or older (10). The median household income in 1999 was \$46,612 (10). The unemployment rate in 2002 was 5.1% (11).

The demographics for people with disabilities were partially captured by the 2000 Census, which excluded individuals living in institutional settings and individuals under the age of 5. The 2000 Census reported 61,951 individuals in Raleigh with disabilities in non-institutional settings, 22% of Raleigh's population (10). Disability rates vary substantially by race and ethnicity. According to the 2000 Census, 12.5% of Whites and 10.3% of Asian-Americans in Raleigh have disabilities, while 19.8% of African Americans and 16.3% of Hispanics have disabilities (10).

Raleigh and Wake County experience higher incidences of some developmental disabilities, such as autism, than other areas in the state, since people seeking medical care are drawn to nationally recognized providers in this area (12)

### **Business, Economy, and Research Triangle Park**

Raleigh combines with neighboring towns Durham and Chapel Hill to form the Research Triangle Park, a complex which covers 6900 acres and includes 147 organizations with 42,000 employees, of which 106 are research and development entities with affiliations with NC State University in Raleigh, University of North Carolina (UNC) in Chapel Hill and Duke University in Durham (13). The additional presence of world-renowned hospitals at UNC and Duke, as well as Raleigh's role as the county seat and state capital, make education, healthcare and government Raleigh's top three industries (14). With its rapid pace of growth and with unemployment rates consistently lower than those of the state and nation as a whole (11), Raleigh receives frequent national recognition as a top location for business and employment, including being deemed "#1 Best Place to Live & Work," by *Employment Review Magazine* in 2003 (15).

The economic picture, however, is less promising for Raleigh residents living with disabilities. For example, 30% of males and 37% of females with disabilities ages 21-64 are unemployed (16). These figures rise significantly for individuals who are also part of a racial minority group as, for example, 36% of African American males and 59% of Hispanic females with disabilities in this age group are unemployed (16).

### **Political and Budget Climate**

Raleigh is governed by a Mayor, a city council, and a city manager. Mayor Charles Meeker, a Democrat and former city councilor, was reelected to his second term in November 2003 (17). Raleigh is home to the Mayor's Committee for Persons with Disabilities, the mission of which is to help people with disabilities in the Raleigh area participate more fully in all parts of

the community. The City of Raleigh budget for 2003-2004 totaled more than 378 million dollars, at a per capita expenditure of \$1,195 (18). Like many cities and states in the nation, recent years have brought fiscal woes to North Carolina; in the 2001-02 budget year, the state experienced a \$1.6 billion budget shortfall, which was closed by freezing spending, keeping money intended for local governments and seizing money from contingency funds. (19). At the same time, the need for public assistance has increased; for example the Wake County food stamp program served 47.3% more families in 2000 than in 1990 (12).

### **Transportation and Urban Planning**

Raleigh covers 128 square miles and is centrally situated in the 858 square miles that comprise Wake County (20). Raleigh and the Triangle region, unrestrained by physical boundaries, continue to expand outward; the region was listed as having the third largest sprawl in the nation in 2002 (21). This growth contributes to higher vehicle collision rates, more ozone pollution, longer commutes, and less use of mass transit (21).

Raleigh is served by a variety of mass transportation systems, including Raleigh-Durham International Airport, Amtrak, CSX and Norfolk Southern Railroads, Triangle Transit Authority (TTA) Regional Bus System, and Capital Area Transit (CAT) City Bus System (20). An acknowledged barrier facing Raleigh, however, is the amount of traffic created by its growth (22); the number of cars is growing faster than the number of humans, and roughly three times more drivers use I-40, the main artery into the city, than planners had envisioned (23).

According to the 2000 Census, 90% of employees in Raleigh drive or ride in personal vehicles to work, whereas 2.5% use public transportation or taxicab, 3.2% bike or walk, and the remainder work at home or use other modes of transportation (16). Raleigh residents who use public transportation have among the longest (over 60 minutes) home-to-work commute times (16). For approved persons who are unable to drive due to physical or mental disabilities,

Accessible Raleigh Transportation (ART), the paratransit system<sup>1</sup> provided by the City of Raleigh Department of Transportation, offers discounted door-to-door Tier 1 and Tier 2 transportation services for eligible trips within the city limits of Raleigh (24).

## **Recreation**

Known as the ‘City of Oaks’ for its 300 public parks, mini parks, squares, plazas and other green areas (7), Raleigh is also home to museums, theaters, community centers, and a variety of other recreational opportunities (20). City of Raleigh Parks and Recreation Department currently offers separate programs for persons with disabilities, but eventually plans to mainstream persons with disabilities into other general recreation programs (25). Development in Raleigh does not serve all populations equally; for instance, persons in wheelchairs are often unable to access comfortable seating in the numerous new stadium-style theaters that are being built (26). Arts Access, Inc., funded by the City of Raleigh Arts Commission since 1982, works with venues to provide information and technical assistance on acquiring and utilizing sign language interpreters as well as to provide audio description and assistive listening devices at local art events to increase their accessibility (27).

## **Housing**

Affordable housing is a scarce commodity in Raleigh. The average monthly apartment rent (\$763) and the average sales price for houses (\$234,157) are among the highest of North Carolina cities (10). The Raleigh Housing Authority owns and manages over 2,000 subsidized public housing units and administers over 3,000 Section 8 vouchers (28). In 2002, the Housing Authority reported a waitlist of 4,607 families for Section 8 vouchers and 1,881 families for public housing units (12); the Section 8 program is 100% utilized and the public housing occupancy rate is over 98% (28). The Karnes Research Company found that the demand for

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<sup>1</sup> Paratransit is an alternate transportation system for people with disabilities unable to use the bus system.



affordable rental units exceeded the supply by over 27,000 units (12). A 2002 Wake County Community Assessment found availability of affordable housing to be the number one economic health concern in the community (12)

A particularly urgent need is for more affordable *accessible* housing units within the city limits. In addition to North Carolina legislation requiring newly constructed multi-family rental housing complexes to contain fully accessible units, tax credits are granted to builders who construct accessible housing (29). Housing which is up for sale, however, frequently does not fall under accessibility guidelines, nor are the guidelines regarding housing to be sold as strict as those governing rental properties.<sup>2</sup> Furthermore, accessibility guidelines do not apply to existing dwellings, unless they undergo major renovations (29). Additionally, much of the new housing is being built outside of the beltline area, where public transportation is insufficient or non-existent (12).

The NC Division of Social Services works with local agencies to improve housing services for older adults and adults with disabilities through special assistance adult home programs, the Independent Living Services Program, and the Vocational Rehabilitation Program. In early 2004, the Raleigh City Council voted to approve funds for the development of apartments for homeless women with disabilities and their families (30).

### **Health Status of Persons with Disabilities in Raleigh**

Raleigh-specific health data on persons with disabilities are not readily available, however the North Carolina BRFSS (31), the Core Indicators Project (32), and data from the North Carolina Office on Disability and Health (33) provide Wake County and North Carolina level data. Each of these sources defines disability differently and therefore numbers vary across

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<sup>2</sup> Buildings containing four or more units and an elevator, or a percentage of ground floor units in buildings of four or more units with no elevator (29).

sources.

According to the 2001 BRFSS study, the top five self-reported ability limitations among people in North Carolina were musculoskeletal, circulatory, respiratory, central nervous system, and metabolic/digestive. In 2000, almost one quarter of all North Carolinians and 50% of persons with disabilities reported physician-diagnosed arthritis (34).

Although individuals with disabilities in Wake County were more likely to report having had a routine check-up in the past two years than those without disabilities, they also had a higher likelihood of health risk factors (32). Individuals with disabilities were significantly more likely than those without disabilities to be overweight, to engage in no physical activity, to be sexually assaulted, to have chronic disease, to have cardiovascular disease, and to have more days of mental health concerns (31). They were less likely to get preventative care, such as immunizations (particularly among African-Americans), dental care, and breast and cervical cancer screening (33). Adults with disabilities, when compared with those without disabilities, reported more dissatisfaction with life (12.7% vs. 3.5%) and less emotional support (12.6% vs 5.3%) (31). Self-reported poor health was also more prevalent in the disability population, with 47.8% of adults with disabilities reporting their health as fair or poor, as compared with 5.9% as fair or poor for people without disabilities (33).

An issue for many residents in Raleigh (not only those with disabilities) is access to healthcare. There are many health care providers in Wake County; however growth in providers has not kept pace with population growth. In 1997, there was one primary care physician for every 1,101 residents in Wake County, as compared to the North Carolina rate of one physician for every 467 people (12). According to a Wake County 2002 Community Assessment, transportation to health care provider facilities is a barrier for individuals living outside the beltline, where bus routes do not extend, and for those with disabilities who do not drive. (12).

## **Services for People with Disabilities**

City government services, specifically for persons with disabilities living in Raleigh, are provided by the Department of Parks & Recreation and the Transportation & Transit Division (18). County services for people with disabilities are provided by Wake County Human Services, an agency that now includes many services which include public health and mental health services, services for people with Developmental Disabilities, substance abuse prevention and others. Budget limitations at Wake County Human Services in recent years have resulted in 886 children and adults being placed on the waitlist for Developmental Disability services, the largest in the state, as of July 2002 (35). Wake County also has waitlists for respite care, in-home aide services, housing and home improvement, adult day care, and mental health services (12). The strain on mental health services will be increased with the planned 2007 closing of the Dorothea Dix Hospital, the only in-patient psychiatric care provider in the county that provides services regardless of patient ability to pay (12).

Additionally, a myriad of nonprofit agencies serve people with disabilities in Raleigh. Their programs include vocational rehabilitation, advocacy, housing assistance, health care, food provision, substance abuse treatment, education and tutoring, home care, adult daycare and respite services, and arts access. Some of these agencies provide services to people with specific disabilities, others are cross-disability, and still others provide services to individuals both with and without disabilities. The Triangle United Way hosts a 2-1-1 phone line information service that directs callers to local services appropriate for their needs (36). There are 87 Raleigh programs explicitly for people with disabilities listed in this service, not including government offices or services for the general population that people with disabilities might utilize (36). Finally, there are for-profit businesses that provide services for individuals with disabilities, including sales and repair of assistive equipment and technologies (e.g. wheelchairs, lifts, screen

reading software, etc.) (37).

Overall, the information from secondary data analysis helped guide the development of interview question guides (see Appendix A). In particular, interview questions asked about transportation, employment, access to services, housing, and health in order to elucidate similarities and differences between secondary data sources and the opinions of interviewees. In addition, more general questions asked about the strengths of the community of persons with disabilities in Raleigh and the challenges faced by this community; these latter, more general questions were posed to bring to light additional issues to those uncovered by secondary data sources.

The following Results section of this document contains a description of views of community members, service providers, and the AOCD team as to the overarching strengths and weaknesses of the Raleigh community, and the issues of housing, transportation, the built environment, communication, employment, and access to services, as the information was collected from interviews and field observations. Following the Results is a report on the Raleigh Community Forum, including forum background, forum planning, promotion and marketing, and a discussion of forum activities. A section on the Methodology of AOCD follows, and Conclusions and Next Steps close the document.

## **Results**

Below are the major findings from interviews and from field notes relating to the six domains identified as most important and most changeable by the community (see Forum Planning and Methodology sections for details on the interview and field note process, as well as on the process of coding interviews, grouping themes into domains, and domain prioritization; see also Appendix H for a table of codes). An overview of the overarching domains recurrent throughout interviews is presented below, as is an analysis of the similarities and differences between the perspectives of service providers and those of community members. A tabular convergent analysis that also includes secondary data sources is available in Appendix G.

### **Overarching Strengths and Challenges**

#### *Strengths*

One of the most common themes to emerge from the interviews was the high quality of life experienced by residents of Raleigh. Community members (individuals with disabilities in Raleigh) and service providers agreed that “Raleigh is a great place to live,” that it was a great place to raise a family, and that it was one of the most accessible cities in North Carolina and worked hard to maintain a ‘disability-friendly’ reputation. Community members and service providers commented on the wide array of available services and indicated that Raleigh was home to a number of innovative and exceptional programs; for example, many said the paratransit system was the best in the state. Service providers detailed current efforts to improve access while community members expressed the opinion that services were improving. Other important strengths included diversity in the community and the presence of active disability advocacy groups and strong informal support networks. Almost every interviewee discussed some aspect of the many recreation and leisure opportunities available in Raleigh, including accessible museums, theater performances with audio description, and accessible sports programs.

## *Challenges*

Without exception, interviewees indicated that a lack of awareness by the general public about disability issues caused many of the challenges facing people with disabilities. One community member commented, “I think the biggest thing is education” and another stated that, “...there is a need for social sensitivity.” They expressed the feeling that the general public was unaware of the issues/needs of people with disabilities, and was uncomfortable or avoided interaction with people with disabilities. There was significant overlap between community members and service providers on this issue. Individuals with disabilities, however, tended to discuss a lack of awareness, negative attitudes, and paternalistic treatment by service providers and the general population, while service providers frequently also raised the issue of discomfort or uncertainty about the best way to be helpful and to communicate. Many community members suggested implementing school programs, sensitivity trainings, media campaigns, and targeting the political environment as a way of enhancing awareness around accessibility issues, language, and etiquette<sup>3</sup>. Service providers suggested educating themselves and other service providers on accessibility issues, as well as the social implications of disability and collaborating with the community through task forces and focus groups.

Another challenge mentioned primarily by service providers was an insufficiency of resources to meet needs in the community. Service providers discussed the recent rapid growth in the city, which had not been matched by a growth in resources and that had resulted in long waitlists for many services. Service providers mentioned that it was expensive to become and remain fully accessible (with regard to materials, programs, and building structure), and that agencies do not budget resources to ensure ongoing accessibility. Service providers felt that there wasn't enough money to meet the demands from the community; however they felt that there was

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<sup>3</sup> Etiquette concerns primarily were related to parking and service animals.

a noted discrepancy between this lack of basic resources and the impressive cultural activities and resources in Raleigh. Overall, there was a perception by service providers that the inadequacy of funding generally resulted in temporary band-aid solutions rather than system-wide changes.

While these strengths and challenges were discussed at length by interviewees in general terms, they were also woven into conversations about the specific domains detailed below. Lack of awareness and inadequate resources recurred within all six domains, and often interviewees balanced concerns about specific issues with comments on what Raleigh was ‘doing right.’

## **Housing**

### *Community Member Perspectives*

“Just because they say [housing is] accessible, does not mean that it really is, and what’s accessible for one person is not for another.”

Overall, there was a sense that fully accessible and/or visitable<sup>4</sup> housing in the city of Raleigh was neither readily available nor attainable, nor very affordable for people with disabilities. Community members acknowledged that the lack of affordable housing was a major problem for everyone, but felt it was of particular concern for people with disabilities who often had a fixed income and needed to live within the city limits due to their reliance on public transportation. Housing was seen as a multifaceted problem: it was extremely expensive, hard to modify, not accessible and in short supply. This was an issue for renters and homeowners of all financial levels, as there was a lack of section 8 housing, accessible houses for sale, and accessible vacancies in stand-alone apartments, apartment complexes, and duplexes. One community member recounted, “I was looking for housing a couple of years ago and I was extremely discouraged that there were really no houses around that could...be made accessible without a fairly significant investment. Some are just inaccessible from the start.” Another stated,

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<sup>4</sup> “Visitable” is a term used to describe housing that is accessible to people of all abilities. It is built in a manner that is easily modifiable to improve accessibility.

“As far as accessibility for people with disabilities, and the construction of new homes... it’s just not really available.” Another problem often mentioned was a lack of knowledge about accessible design among contractors, architects and landlords; some community members explained, “Apartments advertised as handicapped accessible are not really accessible, they’re better suited for seniors and people with arthritis,” and “...they think handle bars in the bathroom equals handicapped accessible but that is NOT true.” Inaccessible housing also had social ramifications, as one community member stated, “Regardless of how much the common facilities may have been improved, most people live in houses I can’t even visit without a major effort, without a major project at hand; that’s a severe barrier to our social life . . . it means that usually my friends come to see me and I can’t go to see them.”

#### *Service Provider Perspectives*

“It’s a God-given right to be able to have access to your home, from your home, for anyone who wants the independence without having to rely on other people.”

The service providers expressed the belief that Raleigh needed to create more affordable and accessible housing. Service providers were also concerned about people with disabilities living on the street or in nursing homes. Another service provider wanted to bring the visitability<sup>5</sup> movement to Raleigh, “I would love to see the visitability movement catch on and be expanded here and incorporate it into our building codes and all because that’s essentially how it gets infused into a community.”

#### *Comparison of Community Member and Service Provider Perspectives*

Housing was a more frequently expressed concern for community members than service providers. Both community members and service providers felt there was a need for more

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<sup>5</sup> Visitability refers to a movement to construct housing that is accessible to people of all abilities built in a manner that is easily modifiable to improve accessibility.



affordable and accessible housing in Raleigh. Community members saw the issue as an overwhelming problem with no easy solutions, whereas service providers had ideas about how to improve housing (related to visitability and creation of affordable housing) and seemed to view it as something that is already improving.

#### *Team Observations from Field Notes*

During their experiences and interactions in the community, the AOCD team heard concerns expressed about the scarcity of affordable, safe, and accessible housing in Raleigh. Housing was a recurrent agenda item at meetings the team attended; discussions normally revolved around the long waitlists for publicly subsidized housing, and that once available, structures were not always physically accessible to persons with some disability types.

### **Transportation**

#### *Community Member Perspectives*

“I don’t go to church on Sundays because there is no transportation.”

While Raleigh’s transit/paratransit situation was perceived as better than that in most cities and was viewed to be improving, transportation continued to be one of the chief frustrations for people with disabilities, disconnecting them from work, recreation, and contact with others. The biggest complaint was the limited schedule and the lack of service in the evenings and on Sundays. As one community member explained, “And it’s really hard, during State Fair time [or] on a Sunday, don’t even try to get a cab. I’m telling ya, don’t try because you won’t get one, or it will be three hours.” Many also feel that bus routes were long and indirect and had an inadequate number of stops. Several community members commented that extensions of routes and schedules would benefit the general population, not just people with disabilities.

There was also frustration with the accessibility of the buses, such as the need to fix external speakers<sup>6</sup> to ensure adequate sound quality of announcements. Interviewees noted that some bus drivers didn't make announcements and would pass people standing at bus stops.

Affordability was a concern for people with and without their own transportation. Some community members tried to reconcile costs with time, "So there's kind of a moral dilemma there, ya know, do I want to take the cab home for \$1.50 and be home an hour early or do I want to take the bus because it's free but it takes an hour?" One community member reported often having to argue with the cab company about the money or the funding. For those who owned a car, the maintenance of accessible vehicles was very high; one car owner said, "Repair, initial purchase, and upkeep are high. The repair facilities don't always have ability to work on accessible vehicles and you have to replace [parts] more often."

#### *Service Provider Perspectives*

"Education can get better and better and that is wonderful. However, even though you are as smart as can be, if you don't have a way to get to school or there's no way for these services to get to you – it's not helping you."

Service providers were well aware of the issues pertaining to public transportation, as transportation was a major barrier to the provision of services. They felt that transportation was expensive and very limited. While some providers were able to provide transportation, many lacked the funds for door-to-door service. One provider said the lack of transportation to services had increased the anxiety of consumers with cognitive disabilities. Service providers felt that the transit system was confusing and that there was a need for technological enhancements, "...like more talking buses and a reservation system." Some also felt that advancements like lifts and scrolling displays had helped the buses become more accessible to people with mobility and

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<sup>6</sup> External speakers on buses provide audio to describe bus routes and to announce stops.

communication disabilities. Service providers desired more public transportation services (more routes and more frequent trips) with better and safer pedestrian connections to transit.

#### *Comparison of Community Member and Service Provider Perspectives*

Service providers and community members were in almost unanimous agreement on the transportation issue. The comments of service providers indicated that community members had been very vocal about transportation and had made clear to providers their needs and desires on this issue. Service providers were quite aware of community member's concerns about the lack of Sunday and evening service. Service providers also agreed that it was hard to live or travel outside the Raleigh city limits if one did not have a personal mode of transportation. Transportation was extremely important to people with disabilities, as one community member stated, "I know I keep dwelling on transportation but...probably one of the biggest obstacles for a people with disabilities [is] getting somewhere."

#### *Team Observations from Field Notes*

The impact of having to rely on public transit as a primary means of travel, as many persons with disabilities do, was experienced first-hand by the team and recorded in field notes. Because of limited, tardy, or inaccessible transportation services, persons with disabilities in Raleigh were sometimes unable to fully participate in meetings attended by the team including monthly Universal Disability Advocates meetings, the forum planning committee, and community events such as the NC Disability Action Network Disability Congress in Cary, NC. As a result, persons with disabilities who used private transportation were seen to be more involved in community activities.

In their field notes, team members recorded perceptions both of praise and frustration for the accessibility and availability of transportation services in Raleigh. In discussions with Raleigh citizens, the transportation system was lauded for involving persons with disabilities in advisory

roles and for continuing to improve services as resources allowed; the team also observed concerns being voiced over the complicated and confusing nature of transit services, the requirement to schedule all paratransit Tier 2 rides in advance, and the potential loss of services in the event of a merger of larger transit providers.

The team also observed that the built environment was not always supportive of transportation needs of people in the community. Some bus stops were located across major thoroughfares from service agencies, and several stops provided no shelter from poor weather conditions.

## **The Built Environment**

### *Community Member Perspectives*

“The main problem I have to face is - are those places integrated for folks like me? In my case, are there architectural barriers? For people with other disabilities those barriers could be of a different ilk.”

Community members emphasized that sidewalks, parking areas, and buildings in Raleigh are frequently inaccessible, either partially or entirely, to some people with disabilities, and that Raleigh is not very pedestrian friendly. Examples of community member comments included, “...facilities are not accessible,” “...parking spaces are too small for vans and [wheelchair] ramps,” “...my biggest complaint is sidewalks” and “...bathrooms are not very accessible.” Many people talked about the lack of accessibility in privately owned buildings; bathrooms and parking were cited as the most problematic. As one woman said: “I generally make a point to schedule things so that I don’t need to use a bathroom when I’m out and about...”. Others issues that emerged were the inaccessibility of doctor’s offices and the narrowness of aisles between racks in clothing stores. Some community members said that newer restaurants, like fast food chains, were generally more accessible than older traditional restaurants. People also mentioned the lack of customer assistance in grocery stores and gas stations, which were frequently self-serve. Others

said that there were some places they avoided all together due to inaccessibility such as gym facilities, and educational institutions. Conversely, there were also community members who said that Raleigh was fairly accessible and amenable to change; for example, "...a curb cut issue was raised downtown and it got fixed easily."

### *Service Provider Perspectives*

"It's amazing to me...when you can go into a new facility that has been built and look at the ramps and things and see how nice they are and then you go into an older facility and you look at the ramps that were built at that time and they're not compliant."

Privately owned buildings (like churches and restaurants), and older buildings in Raleigh were frequently mentioned by service providers as being the most inaccessible facilities. A few service providers expressed that building codes encouraged new buildings to comply with ADA guidelines. However, another felt that even new buildings were inaccessible due to lack of ADA compliance: "The enforcement of ADA codes is so substandard it's unbelievable. There are buildings being built everyday that are so inaccessible..." Inaccessibility of parking spaces for wheelchair vans was another design issue mentioned. On a more positive note, one service provider mentioned that audible signals at cross walks in downtown Raleigh were a great accommodation.

Not all service providers were sensitive to the issues posed by barriers of the built environment to people with disabilities. One service provider indicated a lack of a sense of personal responsibility to ensure that buildings were accessible, and commented that changing old buildings caused them to lose their unique character.

### *Comparison between Community Member and Service Provider Perspectives*

Community members and service providers both addressed issues regarding ADA compliance. In general, community members focused more on specific accessibility issues that

affected them on a day-to-day basis such as parking, sidewalks and general accessibility, whereas service providers talked more about the laws surrounding ADA compliance, and accessibility depending on type of ownership (private versus public) and on age of buildings. Community members tended to discuss accessibility in terms of all aspects of the built environment, whereas service providers focused on issues like building codes, and were generally more optimistic than community members about the level of accessibility of new buildings in the city.

### *Team Observations from Field Notes*

The team documented many instances of buildings, streets, parking lots, and sidewalks in Raleigh that were not accessible to persons with disabilities. Examples included: curb cuts in place on only one side of the street; grates, cords, or cracks in the sidewalk that could hinder wheelchair passage or pose an obstacle to a person with mobility limitations or vision loss; buildings that lacked fully accessible entrances and exits; major thoroughfares without functioning audible crosswalk signals; and parking spaces designated as accessible that were located far from wheelchair ramps or across a lane of traffic from building entrances.

## **Communication**

### *Community Member Perspectives*

“I mean, it’s a challenge because there’s limited resources to get print translated into speech or Braille.”

Community members felt that service provider’s lack of knowledge about accessible communication negatively impacted health, education, and the quality of life for people with disabilities. Community members from different disability groups focused on different types of communication barriers. Those with vision loss were frustrated by the lack of alternate formats for printed materials including the lack of accessible educational materials at local universities and Braille menus at restaurants. One community member said, “I have a hard time using restaurants. I tend to go to the same place and order the same thing because then you know what’s

on the menu.” One community member mentioned that even a disability advocacy organization had failed to send out materials in alternate formats. Others mentioned that needing assistance in grocery stores was becoming problematic as more employees were non-English speaking. People who were hard of hearing or deaf were upset by the lack of American Sign Language interpreters and TTY (teletype) services<sup>7</sup> which often caused problems in communicating with medical care providers. One community member also stated, “If someone who is deaf happens to lose power, they have no way to communicate with emergency services.” Others mentioned how the “whole medical community has a long way to go” before being accessible to people who are deaf and hard of hearing. Many individuals who are deaf and hard of hearing had suffered when dealing with providers who didn’t find ways to communicate critical health information, such as having their TTY calls hung up on by pharmacists inadequately trained in using TTY, waiting long amounts of time for hospitals to find interpreters, and dealing with physicians who did not want to pay for interpreters.

### *Service Provider Perspectives*

“Language barriers are a big problem these days because of the change in population around here. We find ourselves continually needing Spanish language or some form of Chinese language.”

When asked about communication issues, service providers tended to focus on English language barriers impacting service provision, rather than communication issues faced by people with disabilities. Some felt that they were meeting demand for communication access, as one service provider explained, “I think we are very advanced in our ability to have access to interpreters as well...we’ve really come a long ways in being able to have access to hire people who have language abilities, specifically in Spanish.” Several service providers admitted not

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<sup>7</sup> TTY is a telephone relay system that allows deaf and hard of hearing individuals to communicate by telephone with the use of typed messages.

having multilingual websites, brochures, or audio description. One provider of recreational services acknowledged, “We don’t...have an answer for the non English component although that’s certainly something to consider. It’s such a growing primary language in Central North Carolina...so that’s something we should consider and we’re not addressing in any particular way.” One service provider working with the deaf and hard of hearing said that there was a large Hispanic deaf community but that “Spanish sign language is very different from American sign language.”

#### *Comparison of Community Member and Service Provider Perspectives*

The community members and service providers contextualize communication barriers very differently. People with disabilities are concerned with the lack of sign language interpreters, TTY services, and Braille materials, whereas service providers focus more on insufficient bilingual materials and staff. Community members feel that service providers need to recognize ASL as another language similar to Spanish, as one member stated “written English is difficult for those whose first language is ASL English is not our first language, I was born hearing and acquired language so I am bilingual, but I do struggle with English, always thinking - how do I put this in English?”

#### *Team Observations from Field Notes*

The AOCD team observed both communication failures and successes between persons without disabilities and persons with disabilities, as well as between persons of differing disability types. At various venues in Raleigh, as well as at meetings of disability organizations, the team witnessed a lack of large print and/or Braille materials, in addition to a failure to adequately explain visual and physical components of activities in the detail necessary for comprehension by those with vision loss. Conversely, the team observed a statewide event held for people with disabilities provide many accessible formats of information, including audio



description of visual elements of the event, transcription of all verbal communication on screen for use by attendees who were hard of hearing, sign language interpreters, and Braille versions of documents. Team members also attended lunch at a Raleigh restaurant that provided Braille versions of menus to people in the group with vision loss. Subsequently, the team made efforts to create documents and conduct activities in a way that was accessible to all participants (e.g. the use of email, Braille, and large print documents); community feedback to the team on these efforts suggested the successful accommodation of many community members.

## **Employment**

### *Community Member Perspective*

“Since after 22 years of being happily employed I finally got laid off and joined the ranks of the 75% or so disabled people unemployed. That’s a figure that hasn’t changed since ADA was passed.”

Many people in the community talked about employment as a major issue for people with disabilities; high unemployment rates were mentioned repeatedly throughout interviews. In addition to unemployment, underemployment was also a central theme; people had great difficulty finding work at their education level, and commonly took jobs that did not require the degrees they had earned: “I’ve seen blind people that had several degrees and doctorates and all that, and still have trouble finding a position in the area they wanted to....[you] end up taking a job that isn’t really what you had originally planned to do”. Community members discussed that securing employment was especially difficult for people who were blind or had low vision. Some mentioned they felt problems had been compounded by the recent economic downturn, and that many people had been laid off as a result. Transportation was included by some as “...an issue for employment,” since bus routes were limited and did not run late at night. People also felt unable to work, either due to their disability, or out of fear of losing benefits if they became

employed. One woman, however, felt that companies had been very flexible in accommodating her needs when she developed a disability.

### *Service Provider Perspective*

“...[My client] has been offered a lot of positions on the phone because of her resume. But...the job interview is over as soon as she gets in the door.”

Views were varied among service providers on the issue of employment for people with disabilities. Some service providers said that people with disabilities faced overt discrimination and underemployment even by companies serving people with disabilities. Another agreed that discrimination existed, but felt that this was sometimes used as an excuse, when the real issue was an attitude problem on the part of the individual with the disability. A few individuals talked about services provided to help people with disabilities, such as financial assistance for those who could not work, or job placement and job coaching assistance. Someone identified social interactions as the main challenge in enabling people with developmental disabilities to be able to retain jobs, “For people with developmental disabilities, what we experience is...you can learn how to do the job, but then knowing what to say or not to say to the pretty women working next to you is a little harder.”

Another service provider mentioned transportation and limited bus service as a barrier for people trying to work, “We have to look at the bus service, the coverage area, and the time it covers when we start a job search.” One service provider commented that people with disabilities had the choice of whether or not to work due to their ability to receive government financial support, while someone else commented that people who developed certain disabilities, like multiple sclerosis, were unable to work at all due to their disability.

### *Comparison of Community Member and Service Provider Perspectives*

Service providers tended to be less in agreement regarding employment than community members, who for the most part brought up similar issues to one another about lack of jobs and underemployment for people with disabilities. Service providers were generally more focused on specific services provided to the unemployed, on specific disability types served, and on attitudes of people with disabilities as contributing factors to their employment situations, whereas community members tended to discuss broader issues such as systematic discrimination in employment.

### *Team Observations from Field Notes*

A great deal of concern and anxiety over employment for people with disabilities was expressed to the team throughout the AOCD process. While the team was in contact with both employed and unemployed persons, it became evident during the team's time in the community that job prospects for persons with disabilities were limited. The perception of team members is that employment within organizations and government offices intended to support individuals with disabilities was especially troublesome due to limited availability of positions in these organizations, high competition for positions due to the large number of people with disabilities seeking work, and the lack of sufficient funding to make open positions accessible to people with disabilities.

### **Access to Services**

#### *Community Member Perspectives*

“...many of the services that are available in the city exist but there is a disconnect between the people knowing about the services and the services knowing about the people.”

Lack of knowledge about available services, and lack of collaboration and coordination of services emerged as themes in interviews with community members. There was a sentiment from

some community members that agencies needed to do a better job of coordinating services more: “I would make [there be] more coordination as far as [service provision] is concerned.” Other people felt that agencies did successfully collaborate, and that this was a strength of Raleigh: “As a community in Raleigh, that’s one of the great things here...our...senior groups, the Federation, the Council, and UDA...bond together ...I think working together on things has been massive.” Others indicated that service providers were good about communicating with one another about services they provided.

### *Service Provider Perspectives*

“There is no central, what I would call database, where service providers like myself can register and someone new to the area could look up in the phonebook and say ‘Okay, this is who I need.’”

Collaboration with other agencies emerged as a theme in interviews with service providers who, when thinking about assets in Raleigh said: “one of the biggest strengths is partnerships.” One provider said, “Some of the strengths are that the people who are in the services that refer to us are so dedicated ...even though we don’t advertise, they take the time and energy to find out about us. They share their resources with each other.” Statements were also commonly made, however, that there was a *lack* of collaboration between service providers. When discussing changes needed in service provision, one person said, “I would make [there be] more coordination.” Some people suggested that service providers did not talk enough amongst themselves. Others brought up that it was tough to know where the services were, and who provided what service, “Understanding where to access services is difficult... *learning* where to access services [is difficult].” One provider commented that this difficulty existed because there wasn’t a single list or directory to help service providers refer clients to others. Another person

said, “I think one of the biggest obstacles is learning where to go to access information that is available.”

### *Comparison of Community Member and Service Provider Perspectives*

In general service providers spoke more about lack of knowledge about existing services than did community members. This may be explained in part by the fact that community members often spoke about learning of services through their personal networks in the community, rather than through referrals from the agencies that they use. Additionally, because the team primarily reached ‘well-connected’ community members during the AOCD process (see the Methodology ‘Limitations’ section), interviewees were likely to know of services that existed through their personal networks and may have been less reliant on service agencies for that information.

### *Team Observations from Field Notes:*

The team documented barriers to accessing services at multiple levels as they were described informally by members of the community; for example: the availability and ease of access to information about services that are offered in Raleigh, and the accessibility of transportation to and from service facilities that are widely spread throughout Raleigh and Wake County. In one instance a community member raised the question of why he had been eligible for a particular service for ten years and had never known about the service; a similar situation occurred when several members of the community were not aware that there was, in fact, weekend public transportation to the nearby city of Cary. It seemed to the team that in these situations, one or more persons (but never all) were aware of available services. Limitations of the physical accessibility of buildings that housed service providers were experienced and recorded by the team directly.

## Community Forum

### **The Forum Background**

The six domains discussed in this section were presented back to the community at a Forum held on April 19, 2004. The Community Forum, or community meeting, was the integral last stage of the Action Oriented Community Diagnosis. Its goal was to bring together community members and service providers to understand each other's perspectives, celebrate accomplishments and work together for community change. To accomplish this goal, the forum included an overview of the AOCD process, a summary of the results of the research, a description of the main domains that had emerged as areas in need of change, and finally small group discussions meant to identify clear action steps for change with assigned ownership. The creation of these action steps was intended to translate viewpoints into action by building on existing strengths or creating new directions for improvement and to place accountability for future action in the hands of the community.

### **Forum Planning**

The team formally began planning for the forum in mid March. Planning committee members were recruited through individual interviews and focus groups as well as via recommendations of others by interviewees. There were twelve individuals from Raleigh on the planning group, including service providers, persons with disabilities, and family members of persons with disabilities. The group also reflected a mix of disabilities. Eight individuals attended each meeting in addition to team members. Individuals who could not attend due to transportation or other reasons provided input via email.

The planning committee met once a week for three weeks prior to the April 19<sup>th</sup>, 2004 Forum. The first planning committee meeting on Thursday April 1st was devoted to describing the background and methodology of the AOCD process to the planning group members as well as

to getting advice on logistical issues related to the forum. At the second planning meeting on Wednesday April 7th, members of the team demonstrated an empowerment education technique that team members hoped to use in small groups at the forum to prompt discussion and the creation of action steps. This meeting also was devoted to a discussion of accessibility needs and logistics for the forum. At the final meeting on Thursday April 15<sup>th</sup>, planning committee members were presented with a list of the 12 domains most frequently mentioned (more than 15 times) during community member and service provider interviews (see Appendix H for a table of codes and the number of times each was mentioned in interviews) Then, the planning committee narrowed down the top domains from 12 to 6 based on a discussion of the changeability and importance of each domain. Housing, Transportation, the Built Environment, Communication, Employment, and Access to Services were the top domains that emerged from the narrowing process. The Communication domain was further narrowed to focus specifically on communication with health care providers.

### **Forum Promotion/Marketing**

In order to promote the forum, AOCD preceptors at the NC Office on Disability and Health assisted the AOCD team in designing a forum advertisement flyer (see Appendix D) and made copies for distribution within the community; many were given out at a disability event held two weeks prior to the forum. The AOCD team sent personalized thank you letters to all interviewees that included invitations to the forum. An additional 60 flyers were sent on paper and via email to service providers and politicians in Raleigh. One team member and preceptor drafted a press release for radio and newspaper, which was subsequently published in the *Raleigh News and Observer*. Two members of the AOCD team advertised the forum by participating as guests on “Speak UP, Speak Out, Voices in the Community,” a cable access TV show hosted by Karen Moyer-Stallings, a community member and disability rights activist in Raleigh. Forum

promotion took place informally for three months and formally for the two weeks prior to the forum.

## **The Forum**

The Raleigh team forum was held on Monday April 19<sup>th</sup> from 6:00-8:30PM at the Hudson Memorial Presbyterian Church on Six Forks Road in Raleigh. Twenty-five community members and service providers attended the forum. There were two sign language interpreters and all materials were printed in large print and Braille. When guests arrived, they received a nametag and description of the six domains that the planning committee had chosen for small group discussion. They were then ushered to a table where two AOCD team members answered domain-related questions and signed people up for the discussion groups.

After a light dinner, the forum began with opening remarks from team preceptor Fred Johnson who provided some housekeeping information, a brief overview of the AOCD process, an introduction of the team, and thoughts on his experiences working with the team. Jill Kunkel then spoke about the methodology of the AOCD process, providing detail about the team's timeline and use of AOCD methods, and an overview of the agenda and goals for the community forum. Allison Myers provided an overview of the community assets that had emerged from the research prior to Darcie Mersereau's description of the evening's domains. Before moving into break out sessions, a community member read the poem "The Low Road," by Marge Piercy, to inspire action and energy. All attendees received a forum packet, which included an agenda, list of assets, a detailed description of the top domains along with quotes that described them, a copy of the poem "The Low Road" and a forum evaluation form (see Appendix D).

Small group discussions took place for approximately an hour. Because of low interest in the issue of "Transportation" on the night of the forum, this small group discussion did not



occur and the facilitator of this group co-facilitated another discussion. Three small group facilitation techniques (Forcefield Analysis, SHOWED, and ORID) were used to guide the discussions (see Appendix I for descriptions of these techniques). After the small groups ended and the large group reconvened, one representative from each group reported back on their action steps for 15 minutes. Rene Cummins, team preceptor, community member and service provider then discussed the new Center for Independent Living (of which she is the Executive Director) as a strong resource for community collaboration and action on some of the ideas that had emerged that evening. After a very energetic raffle of door prizes, team preceptor Pam Dickens closed the evening by summarizing the forum and reading a short quote by Margaret Mead. A summary of the forum domains, key discussion points and next steps identified in the forum, is provided below.

**Table 1: Forum Small Group Discussions**

<u><b>Domain</b></u>	<u><b>Trigger and Discussion Framework</b></u>	<u><b>Key Discussion Points</b></u>	<u><b>Action Steps</b></u>
<p><u><b>Housing</b></u></p> <p>Discuss the accessibility and affordability of housing in Raleigh</p>	<p>Story created from quotes, the discussion started with ORID and moved to Forcefield Analysis when it became clear that the group was ready to brainstorm action steps.</p>	<p>There is a misperception among builders that making housing accessible costs more.</p> <p>There is a lack of public funding to subsidize accessible and affordable housing.</p> <p>There are very few people with disabilities in the building industry and building associations.</p> <p>There is no organized effort around housing for people with disabilities, but a good source of energy might be people with disabilities currently on housing waiting lists.</p>	<p>Attend and speak at at least one builders convention to raise awareness about the needs of people living with disabilities and access to affordable accessible housing. Ask CIL to make the connection with these groups &amp; try to schedule speakers.</p> <p>Raise awareness among the general public through publicity and collaborations with existing organizations like Universal Disability Advocates, The Raleigh Mayor’s Committee, Center for Independent Living, and the Center for Universal Design at NCSU.</p> <p>Include housing information</p>

		<p>Social Workers may be key resources for working towards accessible and affordable housing.</p>	<p>on an existing disability advocacy website now in a design phase.</p> <p>Long-term goal: build a, visitable housing complex in accordance with the principles of universal design for people of mixed abilities.</p>
<p><b><u>Employment</u></b></p> <p>Discuss unemployment and underemployment for people with disabilities in Raleigh</p>	<p>Adapted poem, ORID</p>	<p>The government does not provide incentives for returning to work because returning to work while on social security leads to the loss of those benefits, even through SS does not cover all necessary expenses.</p> <p>Discrimination is a central problem in seeking and gaining employment.</p> <p>The creation of small businesses by people with disabilities may provide employment opportunities.</p> <p>Make sure that the policies of Vocational Rehabilitation and Center for Independent Living are transparent to the community.</p>	<p>Advocate at the state and federal levels by contacting legislators and the governor to ask: Where do people with disabilities fit into your action plans? And is there an action plan for employment for people with disabilities?</p> <p>Educate the community through existing organizations to register to vote and learn how to effectively advocate for equal employment.</p> <p>Educate community about taking legal action through the ADA when necessary.</p>
<p><b><u>Communication with Health Care Providers</u></b></p> <p>Discuss community awareness in Raleigh on communication issues with health care providers</p>	<p>Adapted poem, started with SHOWED but moved to Forcefield Analysis</p>	<p>We need to target medical professionals during their initial training.</p> <p>People with disabilities can be more vulnerable in the health care system due to low self esteem</p> <p>People with disabilities must also take responsibility for effectively communicating their healthcare needs.</p>	<p>Attend existing community activities, such as health fairs, to increase awareness about this issue.</p> <p>Create a “tips for consumers” brochure focusing on how to advocate for your health needs.</p> <p>Continue providing continuing education courses for health care professionals on this issue.</p>

<b><u>Domain</u></b>	<b><u>Trigger and Discussion Framework</u></b>	<b><u>Key Discussion Points</u></b>	<b><u>Next Steps</u></b>
<p><b><u>The Built Environment</u></b></p> <p>A discussion about sidewalks, parking and building accessibility in Raleigh</p>	<p>Journal entry created from quotes, SHOWED</p>	<p>Service providers and community members agreed on commonality and impact of problem.</p> <p>Improvement will stem from an attitude change among all people.</p> <p>There are many strong community/organizations that could be potential collaborators to address the problem.</p> <p>Begin by partnering with local business community and examining policy changes.</p> <p>Agreement that the environment needs to adapt to the needs of ALL people, not vice versa.</p>	<p>Formation of email group that will arrive at action steps involving collaboration with other organizations</p>
<p><b><u>Accessing Services</u></b></p> <p>A discussion of the challenges around obtaining services in Raleigh</p>	<p>Scenario created from quotes, ORID</p>	<p>An avenue to change is through teaching self-advocacy for accessing service to people with disabilities.</p> <p>Collaborate with rehabilitation provider centers to become tapped into referral resources in the community.</p> <p>Advertising of services provided by service agencies is integral for change in this area.</p>	<p>Have a future forum/conference for service providers &amp; community members to teach/learn about services.</p> <p>Contact Center for Independent Living (CIL) to work with them on this project.</p> <p>Collaborate with CIL to create a sustainable resource network database.</p> <p>Create a grassroots network/friend center.</p>
<p><b><u>Transportation</u></b></p> <p>Discuss Raleigh's public transportation issues</p>	<p>Skit, Small group did not take place</p>	<p>N/A</p>	<p>N/A</p>

## **Methodology**

The AOCD team collected and analyzed secondary and primary data related to Raleigh and people living with disabilities in Raleigh in order to gain, and then to compare and contrast, a variety of perspectives. The purpose of AOCD is to create a complete vision of the community's strengths, challenges, and existing resources on which to build.

Methods for collecting secondary data included the analysis of existing secondary data sources recommended to the team by preceptors, service providers, and community members, while methods for collecting primary data involved gaining entrée and gathering data from documentation of the team's observations in field notes and from semi-structured qualitative interviewing of service providers and community members. Emerging themes in the primary data were then labeled with codes and grouped into larger domains. Guiding the team through the AOCD process were four assigned preceptors: Karen Luken, MSRA, CTRS and Pam Dickens, MPH, who work with the NC Office on Disability and Health (NCDOH) located in Carrboro, NC, and Fred Johnson and Rene Cummins, both members of the Raleigh-based UDA.

### **Secondary Data Methods**

#### *Obtaining Secondary Data*

In order to gain a contextual understanding of issues facing persons with disabilities in Raleigh, the team reviewed 36 secondary data sources documenting Raleigh and/or the situations faced by persons living with disabilities. Specific secondary data sources were suggested to the team by preceptors and by Raleigh service providers with whom the team had spoken or interviewed. Many of the secondary data sources were available through various Internet sites, and some print reports were given by service providers when the team visited their agencies. The team also specifically sought out data related to history, business & economics, social and political climate, geography & urban planning, transportation, recreation, housing, demographics,

health status, and services. Selection of sources and these topics was based on themes found most prevalent in early conversations with community members, as recorded in field notes. This data provided context on life in Raleigh and helped inform interview questions. A complete listing of secondary data sources consulted by the team can be found in Appendix C.

#### *Analyzing/Summarizing Secondary Data*

Secondary data were selected for inclusion based on geographic specificity (i.e. Raleigh-level data was chosen over North Carolina-level data, when available) and relevance to themes already emerging during the team's early experiences in the community. Data was sought about disability-specific aspects of themes (e.g. transportation systems in place for people with disabilities) as well as more general data (e.g. public transit systems as a whole in Raleigh), since it was felt that both of these contexts would be relevant to people with disabilities.

#### *Limitations of Secondary Data*

A possible limitation for the team's secondary data methods involved the team's definition of 'disability.' The team adopted the ADA definition (see Introduction). Secondary data sources, however, did not all use a standard definition and thus varied in their sampling methods (e.g. BRFSS vs. U.S. Census). As a result, the team found the reporting of information to be variable, especially in regard to disability prevalence. Another limitation is that despite the availability of many secondary data sources, the sources consulted by the AOCD team were not always specific to persons with disabilities, nor were they always specific to Raleigh as a city. The team felt it would be inappropriate to include only information on Raleigh or information that was specific only to persons with disabilities, given that life in the city is impacted by issues that transcend disability status or municipal boundaries. Additionally, Wake County and North Carolina health data for persons with disabilities were used as proxies for Raleigh-level disability-related data, which do not exist.

## **Primary Data Methods**

### *Gaining Entree*

Under the preceptors' guidance, the AOCD team began the ongoing process of gaining community entrée by: volunteering at the NC Library for the Blind and Physically Handicapped; attending meetings of UDA and the Raleigh Mayor's Committee for Persons with Disabilities; observing events such as the Assistive Technology Expo., the N.C. State Fair, and the NC Disability Congress; and visiting various businesses in Raleigh. The team, along with Mr. Johnson and Ms. Cummins, also completed a 4-hour windshield tour of Raleigh, the majority of which focused on parts of Raleigh inside the Beltline (see Appendix K for maps of Raleigh). This guided tour allowed the team to learn more about the history, physical layout and built environment, and geographic distinctions of Raleigh. The purpose of gaining community entrée was for the team to learn more about persons with disabilities in Raleigh through first-hand observations and interactions with individuals in the community, and also for community members to observe and interact with the team so as to improve their understanding of the team's presence.

### *Obtaining Primary Data*

Participant Observation. The AOCD team members gathered primary data through field notes; each individual team member documented her own detailed observations of community events, activities, and interactions, as well as of the service delivery system. Despite being engaged in gaining entrée, the AOCD team recognized its role as a group of outsiders to the community and thus analyzed its field note data, which was maintained throughout the AOCD process, from that perspective. Through written observations of events, people, physical geography, and patterns within a community, field notes brought the perspectives and biases of the team members to light. Field notes also provided context and informed the interview process.

Interviews. The research team also collected primary data through the qualitative methods of key informant and focus group interviews. Key informant interviews were held with individuals who were identified and recommended to the AOCD team as being persons whose views and opinions represent those of many others, either among service providers or among community members. Focus group interviews were held with two groups of community members, also to obtain primary data, and to further gain popular perspectives of persons with disabilities. A total of 49 individuals participated in 32 interviews and 2 focus group interviews. These interview participants included community members as well as providers of services to people with disabilities and/or the general population of Raleigh or Wake County. Basic characteristics of interviewees can be found in Appendix B. Prior to starting interviews, the team obtained approval from the UNC School of Public Health Institutional Review Board (IRB), which ensures that all parts of any research involving human participants are carried out in an ethically acceptable manner. Appendix E contains the IRB approval letter for the team's research protocol, methods, and materials.

The Interview Guides. Four types of interview/focus group question guides were developed for use in collecting data: persons with a disability, community members without a disability, service providers, and family members of a person with a disability. These guides and their corresponding fact sheets (also called consent forms) were based largely on those from a 2003 AOCD conducted in Pittsboro, NC for persons living with disabilities, and for which Ms. Luken and Ms. Dickens served as preceptors. Interview guide questions addressed strengths and weaknesses of Raleigh, in relation to housing, recreation activities, transportation, employment, schools, community services, and access to resources and services for the general population and for people with disabilities. Additional questions regarding 'community' and 'health' for people with disabilities were added to the guides following pertinent discussion and observations by the

team during community entrée. The interview guides were purposefully developed in a semi-structured format to allow the interviewer some freedom in probing further into relevant topics or important themes that arose during the AOCD process. Pre-testing of interview guides and fact sheets with various preceptors and another outsider revealed necessary changes and improvements to be made in the interview materials by the team members. Guides and fact sheets can be seen in Appendix A.

Participant Selection and Recruitment. Protocol for recruiting participants began with recommendations from preceptors and UDA members about agencies, service providers, and persons with disabilities. Many service providers were contacted using information from public records, but also by referral. Community members were recruited through the use of consent referrals. Preceptors facilitated initial contact with community members by obtaining consent for a team member to call and arrange an interview (using the recruitment consent form, which can be seen in Appendix A). This referral procedure was also used at the end of each interview. Participants were asked to recommend and contact additional key informants who would be willing to be interviewed and represent the opinions of others in the community.

When scheduling interviews, the team asked participants to choose beforehand which type of interview guide they would like the interviewer to use. Doing this allowed the team to bypass the confusion of how to classify service providers, who might also have had disabilities, and avoid the potential limitation that might be posed by the team making that choice on behalf of participants. It also allowed the participants to answer questions about roles with which they most self-identified.

The Interview Process. Two team members traveled to each interview location. One team member served as interviewer and the other served as notetaker. The interviewer read the fact sheet to the participant and then gave time for the participant to ask questions. After questions



were answered and consent was given by the participant, the interviewer gave a copy of the fact sheet, in the format desired by the interviewee. Accessible formats were available. The notetaker tape-recorded the interview (if the interviewee agreed) and noted important verbal and non-verbal responses, as well as environmental factors affecting the interview. No identifying information was attached to the interview data or notes, and data was kept securely in a locked filing cabinet at the UNC School of Public Health when not in use.

### *Coding and Analyzing of Primary Data*

The notetaker produced a transcription of the interview based on the audiotape recording and interview notes. The interviewer and a randomly assigned team member then each coded the transcribed interview, which involved reviewing interview responses and classifying the ideas conveyed. A designated team member was responsible for reconciling differences between the two sets of codes and for entering the data into Excel. Two team members developed a book of codes (See Appendix F) corresponding to recurrent ideas in a sample of six interviews, and the codes were then used as a means of identifying prominent themes, or related coded ideas, from the text of the remaining interviews. Two team members were responsible for codebook revisions throughout the primary data collection process as the need for codes changed.

Transcripts were assigned a label of service provider or community member and then codes and the quotes to which they corresponded were entered into a Microsoft spreadsheet. At the conclusion of data entry, quotes were sorted by code within larger themes. Based on the frequency and contextual weight given to coded data, the team decided that if 15 or more codes related to a theme were found, then the theme would be presented to the planning group for review. Further analysis involved the comparison of service provider and community member perspectives in relation to each of the more prominent themes. A table comparing secondary data findings with service provider and community member perspectives is available in Appendix G.

The process of identifying themes from the participant observations within the field notes began by first coding each team members' notes individually and then separating and re-grouping notes according to event, resulting in up to six perspectives on the same event. Next, recurrent themes were extracted from each event, and finally, the most prevalent themes were grouped across events. Direct observations by team members of situations relating to the themes chosen for the forum were included in the primary data section of this paper.

#### *Limitations of Primary Data*

Limitations concerning primary data collection methods were many. One such limitation was that the AOCD team offered no definition of 'disability' or 'community' when asking questions about such topics during the interviews. The team intentionally wanted to hear responses without imposing a definition on the participants in order to uncover different truths from different perspectives. However, the team recognized that this could create more variability in responses and less interpretable responses if the participant did not offer sufficient information about how he/she defines these words. Another limitation related to interviewing was variation among interviewers in the tendency to probe more or less on certain topics, which could affect the depth of responses and possibly the frequency of themes that emerge throughout the primary data collection research process. Debriefing after interviews and reading of transcripts by all team members served to increase consistency on future interviews; however, some variation remained likely. A further limitation related to intra-team consistency involved the possible variation in coding styles among the team members; yet again, it was hoped that by employing different combinations of coders for each interview, and by having a third team member reconcile intercoder discrepancies, the differences would balance out.

With the short amount of time allotted to complete this AOCD process for such a large group of people in city of Raleigh, the team felt that many aspects of the process were not

completed as thoroughly as possible. The team was not sure that the group of interviewees it reached represented the full experience of people with disabilities in Raleigh. In particular, the team felt that it was most successful reaching community members who were already well-connected to resources in the community and who were active in advocacy efforts. The team also felt that it was less successful reaching individuals in the community of lower socio-economic status and in exploring fully the experiences of family members of people with disabilities. In addition, toward the end of the AOCD process, the team began to become aware of perspectives that it had not been successful in accessing due to internal ideological and personal conflicts in the community. The team also felt that some of these conflicts, as well as the treatment in general of people living with disabilities, could have affected the candidness of some interview responses. The team felt that the short time for the AOCD process also may have limited the analysis of primary data, as the team struggled with how to analyze data from individuals who fit into categories of both community members and service providers. The team would have liked to assess more fully how this duality of roles affected the different perspectives that emerged within the themes.

Despite a growing level of comfort with and awareness of issues regarding disabilities throughout the AOCD process, the team's overall ability to establish and build rapport with community members was likely limited due to the AOCD team's limited knowledge of various disabilities. According to the team's field notes, team members reflected much on communication with persons with disabilities and the appropriate or preferred language to use among them. Moreover, the field notes documented hesitancy among some team members to ask questions openly of persons with disabilities, despite reassurance from community members that it was better to ask rather than to just sit quietly and wonder.

The team also found that there were many sub-communities often defined by different

disability types such that it was necessary for the team to start the process of gaining entrée again for each of the different segments of the community encountered. Similarly, the AOCD team felt that some segments of the community were simply more accessible to the recruitment and interviewing process by nature of their disability, whereas other segments of the community were more isolated and difficult to reach. Given time constraints and the geographic spread of the project area (see Appendix K for maps of Raleigh area), the team attempted to carefully select a mix of disabilities, geographic locations, and key service agency representation among recruited participants to maximize the ability to generalize to the general population of people living with disabilities in Raleigh.

## **Conclusion & Next Steps**

The goal of the AOCD conducted with people living with disabilities in Raleigh was to gather, analyze, and summarize the perspectives of community members and service providers in for the purpose of creating a complete vision of the community's strengths, challenges, and existing resources on which to build. The AOCD team involved in this project was also interested in the influence of the ADA on the presence and functions of community among adults living with disabilities in Raleigh, N.C. The AOCD process culminated in a Community Forum where 25 community stakeholders came together, discussed issues of importance, and created action steps to improve existing situations.

At the conclusion of the AOCD process, the Raleigh team members had identified dramatically different views on the existence of a community of people living with disabilities, even as many people with disabilities in Raleigh have been active participants of several disability organizations, conferences, and public forums apart from AOCD. The AOCD team felt that these different views of community are driven largely by a wide range of life experiences among individuals with disabilities, such as differential access to resources by disability, differing experience with discrimination based on one's disability, and the timing of acquisition and nature of disability.

Despite the continued question as to the existence of a community of people with disabilities in Raleigh, the AOCD team felt as if the AOCD process sparked a new enthusiasm among, at least, the members of Universal Disability Advocates, if not among a greater segment of the population of Raleigh. The heightened energy felt by the team may have been a reflection of our increased awareness to community dynamics, or of an increase in participation and ownership by community members and service providers in the AOCD process of community

change and social action. Conjecture aside, interaction and communication between service providers and community members who, in some cases had not previously met, and in others had not interacted in this type of setting, fostered an environment where information was shared and new relationships were created. The nature of these interactions resulting from the AOCD process elicited what has felt to the team to be a fresh awareness of self and understanding of one's effect on the current situation for the greater community.

The community forum helped set the stage for building upon such awareness and for moving toward more unified action as individuals shared their differing perspectives with each other in a way that elucidated the multiple underlying causes for each issue. Despite superficial congruence between secondary data, service provider interviews, and community member interviews, there seemed to be different underlying factors affecting each perspective. Community members and service providers, with and without disabilities are under different expectations in their roles. For instance, even where there was agreement about overarching goals, differences in rationale and therefore urgency of need might exist between a service provider focusing on the constraints of resources, time, and money and a community member just wanting to tackle personal issues of daily living.

As a result of this entire AOCD process, and given the acknowledged strengths of the Raleigh community, the team gained a firm belief that people living with disabilities in Raleigh possesses great potential for the collective power and energy needed to follow through on the action steps they generated for themselves. The differences and similarities between service providers and community members suggest that dialogue is key to moving forward with action that is sustainable and beneficial for persons with disabilities. Without further opportunity for continued dialogue, the disconnect between the needs of individuals with disabilities and the providers of services may continue as service providers have the potential to continually design

inadequate programs or services that they mistakenly think are useful. In light of this, the AOCD team hopes and recommends that opportunities to continue safe and open dialogue between community members and service providers should continue, particularly now that action steps have been identified by the community. Collaboration and dialogue between Universal Disability Advocates, The Raleigh Mayor's Committee for Persons with Disabilities, the Alliance for Disability Advocates Center for Independent Living, and other disability organizations could provide a foundation for following through with community action steps.

The team presents this document in the hope that it will contribute to the existing body of knowledge supporting and advancing people living with disabilities in Raleigh, North Carolina. Future improvement within the city of Raleigh will be founded on increased awareness and understanding of the barriers facing people with disabilities, the means for removing those barriers, and the strengths and assets people with disabilities contribute to society at the policy, community, organizational and individual levels. Deliberate compliance with ADA regulations and purposeful allocation of resources for accessibility will be central to facilitating this improvement. Continued dialogue between service providers and community members will provide an opportunity to explore subtle differences in perspective found during the AOCD process. It has been the team's privilege to learn from so many people working to make Raleigh a more inclusive community for people with disabilities, and the team hopes the action steps for change generated by the community during this project will compliment existing work or serve as a catalyst for new action.

## Appendix A: Interview guides, fact sheets, and recruitment consent forms

### Persons with 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 Raleigh and your opinions concerning the strengths of Raleigh and the challenges it faces. We are especially interested in learning about the experiences of persons with disabilities living in Raleigh. 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. Because your opinions are important to us, we would like to tape record the discussion to make sure not to miss anything. At any time during the interview, we can turn the tape recorder off at your request.

1. What is it like living in Raleigh? *Probe: housing, recreation activities, transportation, employment, schools, community services, access to resources and services*
2. What services and businesses do you use in the community? *(anything they can think of; ex: businesses, social services, government services, profit and non-profit services, advocacy groups, etc)*
3. What services and businesses do you not use in the community? *Probe: Are there any that you cannot use? Why?*
4. What are service providers like in the community? *Probe: attitude, behavior, how do they help you*
5. If someone with a disability (disabilities) moved to Raleigh what would you tell him or her are the advantages of living in Raleigh?
6. If someone with a disability (disabilities) moved to Raleigh what would you tell him or her are the challenges of living in Raleigh? *Probe: accessibility, services, discrimination. How does this affect people's health?*
7. When there are problems for people with disabilities, how are they handled? *Probe: accessibility issues, ice storms in the past which caused power outages or limited transportation.*
8. If you were in charge of community services for people with disabilities, what would you do? What if you were in charge of community services for the general population? *Probe: what services would you offer? What programs would you change or cancel?*
9. Do you feel part of a community of people with disabilities in Raleigh? Tell me about it. *(Probe: Talk about the effectiveness of pan-disability community vs. disability-specific....)*
10. Is there anything else that you want to tell us about the Raleigh community?
11. Are there are the people in the community who you think it is important for us to talk to about these issues?
12. 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 A: Interview guides, fact sheets, and recruitment consent forms, cont.

### Community Members 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 Raleigh and your opinions concerning the strengths of Raleigh and the challenges it faces. We are especially interested in learning about the experiences of persons with disabilities living in Raleigh. 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. Because your opinions are important to us, we would like to tape record the discussion to make sure not to miss anything. At any time during the interview, we can turn the tape recorder off at your request.

1. What is it like living in Raleigh? *Probe: housing, recreation activities, transportation, employment, schools, community services, access to resources and services*
2. What services and businesses do you use in the community? *(anything they can think of; ex: businesses, social services, government services, profit and non-profit services, advocacy groups, etc)*
3. What services and businesses do you not use in the community? *Probe: Why don't you use these services?*
4. What are service providers like in the community? *Probe: attitude, behavior, how do they help you*
5. When there are problems in the community how are they handled? *Probe: ice storms in the past which caused power outages or limited transportation*
6. What do you think life is like for persons with disabilities in Raleigh?
7. What do you think are the challenges facing persons with disabilities in Raleigh? *Probe: accessibility, services, discrimination. How does this affect people's health?*
8. When there are problems for people with disabilities, how are they handled?
9. How do you think Raleigh serves persons with disabilities?
10. How do you think Raleigh could better serve persons with disabilities?
11. Is there anything else that you want to tell us about the Raleigh community?
12. Are there are the people in the community who you think it is important for us to talk to about these issues?
13. 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 A: Interview guides, fact sheets, and recruitment consent forms, cont.

### 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 what role your group or organization has in the greater community of Raleigh, and about your opinions concerning the strengths of Raleigh and the challenges it faces. We are especially interested in learning about the experiences of persons with disabilities living in Raleigh. 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. Because your opinions are important to us, we would like to tape record the discussion to make sure not to miss anything. At any time during the interview, we can turn the tape recorder off at your request.

1. Tell us about your agency. What services do you provide? *Probe: Source of funding, how many clients do you serve.*
2. How would you describe the people who utilize your services? *Probe: geographical information, SES, ethnicity, etc.*
3. 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? *Probes: geographic, transportation, cultural, language*
4. What steps do you take to facilitate access to these services?
5. What other agencies provide services to the residents of the communities you serve? What kinds of services do they provide? How successful are they?
6. How would you describe Raleigh? *Probe: Would you define it as a community?*
7. What would you say are the strengths of the communities that you serve?
8. What do you think are the major issues facing persons with disabilities in your community? *Probe: accessibility, services, discrimination. How do these affect people's health?*
9. What services does your organization provide to address these issues?
10. If you were in charge of community services for people with disabilities, what would you do? How would you ensure that persons with disabilities have full access? What if you were in charge of community services for the general population? *Probe: what services would you offer? What programs would you change or cancel?*
11. Have I/we forgotten anything? Is there anything else you'd like to say?
12. Would you like to recommend someone else to be interviewed?
13. We are going to be conducting a community forum 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 A: Interview guides, fact sheets, and recruitment consent forms, cont.

### Family Member Interview 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 Raleigh and your opinions concerning the strengths of Raleigh and the challenges it faces. We are especially interested in learning about the experiences of persons with disabilities living in Raleigh. 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. Because your opinions are important to us, we would like to tape record the discussion to make sure not to miss anything. At any time during the interview, we can turn the tape recorder off at your request.

1. How long have you lived in Raleigh?
2. Do you currently work in Raleigh? (*maybe probe more for contextual info if they just say yes/no*)
3. How would you describe Raleigh?
4. Describe life in Raleigh for adults.
5. Describe life in Raleigh for adults with disabilities. *Probe: jobs, recreation, hangouts, activities, solving differences*
6. What, if anything, makes you proud about living in Raleigh?
7. How do people support each other in Raleigh?
8. What kinds of programs/services are offered in Raleigh? (*anything they can think of; ex: businesses, social services, government services, profit and non-profit services, advocacy groups, etc*); How are services made available to persons with disabilities? *Probe: education, recreation, etc.*
9. How do you feel about the services available for persons with disabilities? *Probe: positive aspects, challenges, etc.*
10. To what extent are families involved or included into services for persons with disabilities?
11. What do you think are the challenges facing persons with disabilities in Raleigh? *Probe: accessibility, services, discrimination. How do these affect people's health?*
12. What do you think are the challenges facing Raleigh in general? *Probe: growth, development, discrimination*
13. How have these challenges affected you and your family personally?
14. What strengths/resources does Raleigh have to help deal with these challenges?
15. If someone were to ask you if Raleigh is a good place to live, how would you respond?
16. If you were the mayor, what you would you do to improve Raleigh?
17. Have I/we forgotten anything? Is there anything else you'd like to say?
18. Would you like to recommend someone else to be interviewed?
19. We are going to be conducting a community forum 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 A: Interview guides, fact sheets, and recruitment consent forms, cont.**

### **Interview Consent Form/Fact Sheet for Member of the Community with a Disability**

#### **WHAT IS THIS STUDY ABOUT?**

You are invited to take part in a research study called a “community assessment”. The “community assessment” is a community study of the experiences of persons with disabilities 18 years and older living in Raleigh, North Carolina. The purpose of the study is to better understand the lives of adults with disabilities living in Raleigh. You are being asked to take part because we want to make sure we hear from individuals with disabilities, family members, other community members, and service providers. We want to learn about the strengths and needs of Raleigh. We want to learn about the services and supports available for people with disabilities.

My name is \_\_\_\_\_. I am a part of a 6 person team from UNC School of Public Health that is conducting a study as part of a class requirement. If you have any questions that we are unable to answer to your satisfaction please contact Darcie Mersereau a graduate student at the UNC or the faculty advisor Eugenia Eng, DrPH.

Darcie Mersereau (919) 966-3919  
UNC School of Public Health  
Dept of Health Behavior and Health  
Education  
Campus Box 7440  
Chapel Hill, NC 27599-7440

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

#### **WHAT WILL I BE ASKED TO DO?**

You will be asked to take part in an individual interview with two team members from the UNC School of Public Health. The interview is a series of questions about life in Raleigh for people with disabilities. An example of a general question is, “How would you describe Raleigh?” An example of a more specific question would be, “How do you think Raleigh serves persons with disabilities?” There are no wrong answers or bad ideas, just different opinions. We are looking for points of view, so say what is on your mind. We are interested in your opinion and experience as a community member with a disability. If you do not feel comfortable answering a question or do not have an opinion, just let us know. You do not have to answer every question.

The interview will take around 30 to 60 minutes of your time. We would like to interview you one time, but we hope you will also attend our community forum in April. At the community forum you can hear and discuss the results of the community research.

If you agree to take part in the interview, we will be recording your responses on a piece of paper. Also, with your permission we would like to tape record the discussion to make sure not to miss anything. Only members of our group will listen to the tapes. The tapes will be erased after our study is over. The tape recorder can be turned off at your request at any point during the interview. Before the interview starts we will ask your permission to tape record.

#### **WHAT ARE THE RISKS AND BENEFITS OF MY PARTICIPATION?**

There are few physical, psychological, and social risks associated with participating in this study.

## **Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.**

The questions for the participants will not be offensive, threatening, or degrading. The interview will focus primarily on the strengths, weaknesses, and directions for development for the Raleigh community. Your name and identifying information will not be attached to interview data. The data will be kept in a secure, locked cabinet at the School of Public Health. You have the option of not answering any question(s) and of turning off the tape recorder at any time. You also have the option of stopping the interview at any time.

Your participation may help to make things better in Raleigh over time, and you may have the direct benefit of having the opportunity to express your opinion. Your decision to take part in this study will not affect any of the services you receive or might receive. You can say yes or no to our request, it will not change any services you can get.

### **ARE THERE ANY COSTS?**

There are no financial costs for participating in the study. The only cost is your time.

### **WILL I BE PAID?**

You will not be paid for your participation.

### **SUBJECT'S RIGHTS AND CONFIDENTIALITY:**

If you agree to take part in this study, please understand that your participation is voluntary (you do not have to do it). You have the right to withdraw your consent or stop your participation at any time without penalty or question. You have the right to refuse to answer particular questions. During the interview you may ask that the recording be stopped at any time.

To protect your privacy, any information you provide will remain anonymous. Your name and address may be collected, but it will be written down separately. 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.

Personal information such as age, ethnicity, sex and number of years living in Raleigh may be obtained during the interview. This information will only be collected to help organize our results. All identifying information will be removed from the final report so that your responses and comments will not be linked to you. The members of our research team will be the only people with access to all the data. All notes and audiotapes containing your interview responses will be stored in a secure, locked cabinet at the School of Public Health and will be destroyed in May 2004 at the end of the study.

If you have any questions or concerns about your rights as a research participant, and/or if you want to withdraw from the study at anytime, please do not hesitate to contact Darcie Mersereau or the faculty advisor Eugenia Eng, DrPH (contact information on page 1 of this form).

This project has been reviewed and approved by the UNC-Chapel Hill School of Public Health Institutional Review Board on Research Involving Human Subjects. If you have questions about your rights as a study participant, or are unhappy at any time with any aspect of this study, you may contact -- anonymously, if you wish -- the School of Public Health Institutional Review

**Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.**

Board, University of North  
Carolina at Chapel Hill, CB # 7400, Chapel Hill, NC 27599-7400, or by phone 919-966-3012.  
You may call collect.

Thank you for your time and consideration.

- Do you have any questions about anything I have said so far?
- Do you agree to take part in this interview?
- Do you agree to be tape-recorded?

## **Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.**

### **Interview Consent Form/Fact Sheet for Raleigh Community Member/Family Members**

#### **WHAT IS THIS STUDY ABOUT?**

You are invited to take part in a research study called a “community assessment”. This “Community assessment” will look at the experiences of persons with disabilities 18 years and older living in Raleigh, North Carolina. The purpose of the study is to better understand the experiences of members of the Raleigh community. You are being asked to take part because we want to learn about Raleigh’s strengths and needs regarding services and supports for people with disabilities. We are interested in the views of individuals with disabilities, family members, other community members, and service providers.

My name is \_\_\_\_\_. I am a part of a 6 person team from UNC School of Public Health that is carrying out a study as part of a class requirement. If you have any questions that we are unable to fully answer please contact Darcie Mersereau a graduate student at the UNC or the faculty advisor Eugenia Eng, DrPH.

Darcie Mersereau (919) 966-3919  
UNC School of Public Health  
Dept of Health Behavior and Health  
Education  
Campus Box 7440  
Chapel Hill, NC 27599-7440

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

#### **WHAT WILL I BE ASKED TO DO?**

You will be asked to take part in an individual interview with two team members from the UNC School of Public Health. The interview is a series of questions about life in Raleigh for people with disabilities. An example of a general question is, “How would you describe Raleigh?” An example of a more specific question would be, “How do you think Raleigh serves persons with disabilities?” There are no wrong answers or bad ideas, just different opinions. We are looking for points of view, so say what is on your mind. We are interested in your opinion and experience as a community member and/or family member. If you do not feel comfortable answering a question or do not have an opinion, just let us know. You do not have to answer every question.

The interview will take around 30 to 60 minutes of your time. We would like to interview you one time, but we hope you will also attend our community forum in April. At the community forum you can hear and discuss the results of the community research.

If you agree to take part in the interview we will be recording your responses on a piece of paper. Also, if you do not object we would like to tape record the discussion to make sure not to miss anything. Only members of our group will listen to the tapes. The tapes will be erased after our study is over. The tape recorder can be turned off at your request at any point during the interview. Before the interview starts we will ask your permission to tape record.

#### **WHAT ARE THE RISKS AND BENEFITS OF MY PARTICIPATION?**

## **Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.**

There are few physical, psychological, and social risks associated with participating in this study. The questions for the participants will not be offensive, threatening, or degrading. The interview will focus primarily on the strengths, weaknesses, and directions for development for the Raleigh community. Your name and identifying information will not be attached to interview data. The data will be kept in a secure, locked cabinet at the School of Public Health. You have the option of not answering any question(s) and of turning off the tape recorder at any time. You also have the option of stopping the interview at any time.

Although you may not experience any direct benefits, your participation may help to make things better in Raleigh over time. Your decision to take part in this study will not affect any of the services you receive or might receive. You can say yes or no to our request, it will not change any services you normally use or have access to.

### **ARE THERE ANY COSTS?**

There are no financial costs for participating in the study. The only cost is your time.

### **WILL I BE PAID?**

You will not be paid for your participation.

### **SUBJECT'S RIGHTS AND CONFIDENTIALITY:**

If you agree to take part in this study, please understand that your participation is voluntary (you do not have to do it). You have the right to stop your participation at any time without penalty or question. You have the right to refuse to answer particular questions. During the interview you may ask that the recording be stopped at any time.

To protect your privacy, any information you provide will remain anonymous. Your name and address may be collected, but it will be written down separately. 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.

Personal information such as age, ethnicity, sex and number of years living in Raleigh may be obtained during the interview. This information will only be collected to help organize our results. All identifying information will be removed from the final report so that your responses and comments will not be linked to you. The members of our research team will be the only people with access to all the data. All notes and audiotapes containing your interview responses will be stored in a secure, locked cabinet at the School of Public Health and will be destroyed in May 2004 at the end of the study.

If you have any questions or concerns about your rights as a research participant, and/or if you want to withdraw from the study at anytime, please do not hesitate to contact Darcie Mersereau or the faculty advisor Eugenia Eng, DrPH (contact information on page 1 of this form).

This project has been reviewed and approved by the UNC-Chapel Hill School of Public Health Institutional Review Board on Research Involving Human Subjects. If you have questions about your rights as a study participant, or are unhappy at any time with any part of this study, you may



contact -- anonymously, if you wish -- the School of Public Health Institutional Review Board, University of North Carolina at Chapel Hill, CB # 7400, Chapel Hill, NC 27599-7400, or by phone 919-966-3012. You may call collect.

Thank you for your time.

- Do you have any questions about anything I have said so far?
- Do you agree to take part in this interview?
- Do you agree to be tape-recorded?

## **Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.**

### **Interview Consent Form for Legal Guardian of a Person with a Disability**

#### **WHAT IS THIS STUDY ABOUT?**

We are conducting a community study of the experiences of persons with disabilities 18 years and older living in Raleigh, North Carolina. The purpose of the study is to better understand the experiences of members of the Raleigh community. You are being asked to give permission for the person for whom you have guardianship of to take part in the study because we are interested in their experiences. We want to learn about Raleigh's strengths and needs regarding services and supports for people with disabilities. We are interested in the views of individuals with disabilities, family members, other community members, and service providers.

My name is \_\_\_\_\_. I am a part of a 6 person team from UNC School of Public Health that is conducting a study as part of a class requirement. If you have any questions that we are unable to answer to your satisfaction please contact Darcie Mersereau a graduate student at the UNC or the faculty advisor Eugenia Eng, DrPH.

Darcie Mersereau (919) 966-3919  
UNC School of Public Health  
Dept of Health Behavior and Health  
Education  
Campus Box 7440  
Chapel Hill, NC 27599-7440

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

#### **WHAT WILL I BE ASKED TO DO?**

You will be asked to give permission for the person who you have guardianship over to take part in an 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 Raleigh for people with disabilities. An example of a general question is, "How would you describe Raleigh?" An example of a more specific question would be, "How do you think Raleigh serves persons with disabilities?" There are no wrong answers or bad ideas, just different opinions. We are looking for points of view, so we will encourage people involved to say what is on their mind. We are interested in the participant's thoughts as a community member with a disability. If he or she does not feel comfortable answering a question or does not have an opinion, he or she can just let us know. He or she does not have to answer every question.

The interview will take around 30 to 60 minutes of your time. We would like to interview you one time, but we hope you will also attend our community forum in April. At the community forum you can hear and discuss the results of the community research.

During the discussion we will record what is said on a piece of paper. If participants agree we would like to tape record the discussion to make sure not to miss anything. Only members of our group will listen to the tapes. The tapes will be erased after our study is over. Anytime during the interview the tape recorder can be turned off by request. No one has to answer any questions that they are uncomfortable with. Before the interview starts we will ask for permission to tape record.

## **Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.**

### **WHAT ARE THE RISKS AND BENEFITS OF PARTICIPATION?**

There are few physical, psychological, or social risks associated with participating in this study. The questions for the participants are not threatening, or degrading. The interview will focus primarily on the strengths, weaknesses, and directions for change for the Raleigh community. Names and identifying information will not be attached to interview data, and the data will be kept in a secure, locked cabinet at the School of Public Health. The participant doesn't have to answer any question(s) and we can turn off the tape recorder at any time. He or she also can ask to stop the interview at any time and choose not to be involved in the study.

His or her participation may help to make things better in Raleigh over time, and he or she may have the direct benefit of having the opportunity to express his or her opinion. Your granting of permission will not influence any of the services you or the person for whom you have guardianship receive might receive. You can say yes or no to our request; it will not change any services you or the person who you have guardianship over can receive.

### **ARE THERE ANY COSTS?**

There are no financial costs for participating in the study. The only cost is time.

### **WILL I BE PAID?**

There is no payment for participation.

### **SUBJECT'S RIGHTS AND CONFIDENTIALITY:**

If you agree to allow the person you have guardianship over to take part in this study, please understand that being involved is voluntary (he or she does not have to do it). You have the right to withdraw your consent or stop his/her participation at any time without penalty or question. The person you have guardianship over has the right to refuse to answer particular questions. During the interview he or she may ask that the recording be stopped at any time.

To protect his or her privacy, any information provided by the person you have guardianship over will remain anonymous. Though his or her name and address may be collected, it will be recorded separately and will not be used in any way in the research study or linked to his or her responses. It will only be used to invite you and the person you have guardianship over to attend the community forum.

Personal information such as age, ethnicity, sex and number of years living in Raleigh may be obtained during the interview. This information will only be collected to help organize our results. All identifying information will be removed from the final report so that responses and comments will not be linked to you or the person you have guardianship over. The members of our research team will be the only people with access to all the data. All notes and audiotapes containing your interview responses will be stored in a secure, locked cabinet at the School of Public Health and will be destroyed in May 2004 at the end of the study.

If you have any questions or concerns about the rights of the person you have guardianship over as a research participant, and/or if you want him or her to withdraw from the study at anytime, please do not hesitate to contact Darcie Mersereau or the faculty advisor Eugenia Eng, DrPH

**Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.**

(contact information on page 1 of this form).

This project has been reviewed and approved by the UNC-Chapel Hill School of Public Health Institutional Review Board on Research Involving Human Subjects. If you have questions about a study participant's rights, or are unhappy at any time with any part of this study, you may contact -- anonymously, if you wish -- the School of Public Health Institutional Review Board, University of North Carolina at Chapel Hill, CB # 7400, Chapel Hill, NC 27599-7400, or by phone 919-966-3012. You may call collect.

Thank you for your time and consideration.

- Do you have any questions about anything I have said so far?
- Do you agree for the interview to be tape-recorded?

Thank you for your time and consideration. Please sign this consent form and return by the stated date. Keep the duplicate copy for your records.

I DO give my consent for \_\_\_\_\_ to take part in an interview as  
Name of person for whom you have guardianship

part of the UNC-Chapel Hill School of Public Health's Community Diagnosis in Raleigh, North Carolina.

Guardian Signature \_\_\_\_\_ Date \_\_\_\_\_

## **Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.**

### **Interview Consent Form/Fact Sheet for Raleigh Service Providers**

#### **WHAT IS THIS STUDY ABOUT?**

You are invited to take part in a research study called a “community assessment”. This study will look at the experiences of persons with disabilities 18 years and older living in Raleigh, North Carolina. The purpose of the study is to better understand the experiences of members of the Raleigh community. You are being asked to take part because we want to learn about Raleigh’s strengths and needs regarding services and supports for people with disabilities. We are interested in the views of individuals with disabilities, family members, other community members, and service providers.

My name is \_\_\_\_\_. I am a part of a 6 person team from UNC School of Public Health that is conducting a study as part of a class requirement. If you have any questions that we are unable to answer to your satisfaction please contact Darcie Mersereau a graduate student at the UNC or the faculty advisor Eugenia Eng, DrPH.

Darcie Mersereau (919) 966-3919  
UNC School of Public Health  
Dept of Health Behavior and Health  
Education  
Campus Box 7440  
Chapel Hill, NC 27599-7440

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UNC School of Public Health  
Dept of Health Behavior and Health  
Education  
Campus Box 7440  
Chapel Hill, NC 27599-7440

#### **WHAT WILL I BE ASKED TO DO?**

You will be asked to take part in an individual interview with two team members from the UNC School of Public Health. The interview is a series of questions about life in Raleigh for people with disabilities. An example of a general question is, “How would you describe Raleigh?” An example of a more specific question would be, “How do you think Raleigh serves persons with disabilities?” There are no wrong answers or bad ideas, just different opinions. We are looking for points of view, so say what is on your mind. We are interested in your opinion as a service provider for the community members of Raleigh. If you do not feel comfortable answering a question or do not have an opinion, just let us know. You do not have to answer every question.

The interview will take about 30 to 60 minutes of your time. We would like to interview you one time, but we hope you will also attend our community forum in April. At the community forum you can hear and discuss the results of the community research.

If you agree to take part in the interview we will be recording your responses on a piece of paper. Also, if you do not object we would like to tape record the discussion to make sure not to miss anything. Only members of our group will listen to the tapes. The tapes will be erased after our study is over. The tape recorder can be turned off at your request at any time during the interview. Prior to the start of the interview we will ask your permission to tape record.

#### **WHAT ARE THE RISKS AND BENEFITS OF MY PARTICIPATION?**

## **Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.**

There are few physical, psychological, or social risks associated with participating in this study. The questions for the participants will not be offensive, threatening, or degrading. The interview will focus primarily on the strengths, weaknesses, and directions for change for the Raleigh community. However, one potential risk may be that if you say any bad things about the community or the services you provide in the community and that information is made known, you may be at risk for losing your job. This information could also affect any political career you may choose to have. We will do the best we can to protect you from this risk by not attaching names or identifying information to focus group data and by storing the data in a secure, locked cabinet at the School of Public Health. Participants of focus groups will remain anonymous, but they may know one another. You have the option of not answering any question(s) and of turning off the tape recorder at any time. You also have the option of withdrawing from participation of a focus group at any time.

Although you may not experience any direct benefits, your participation may help to make things better in Raleigh over time. 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, it will not change any services you can get.

### **ARE THERE ANY COSTS?**

There are no financial costs for participating in the study. The only cost is your time.

### **WILL I BE PAID?**

You will not be paid for your participation.

### **SUBJECT'S RIGHTS AND CONFIDENTIALITY:**

If you agree to take part in this study, please understand that your participation is voluntary (you do not have to do it). You have the right to withdraw your consent or stop your participation at any time without penalty or question. You have the right to refuse to answer particular questions. During the interview you may ask that the recording be stopped at any time.

To protect your privacy, any information you provide will remain anonymous. Your name and address may be collected, but it will be recorded separately. 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.

Personal information such as age, ethnicity, sex and number of years living in Raleigh may be obtained during the interview. This information will only be collected to help organize our results. All identifying information will be removed from the final report so that your responses and comments will not be linked to you. The members of our research team will be the only people with access to all the data. All notes and audiotapes containing your interview responses will be stored in a secure, locked cabinet at the School of Public Health and will be destroyed in May 2004 at the end of the study.

If you have any questions or concerns about your rights as a research participant, and/or if you want to withdraw from the study at anytime, please do not hesitate to contact Darcie Mersereau or

## **Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.**

the faculty advisor Eugenia Eng, DrPH (contact information on page 1 of this form).

This project has been reviewed and approved by the UNC-Chapel Hill School of Public Health Institutional Review Board on Research Involving Human Subjects. If you have questions about your rights as a study participant, or are unhappy at any time with any aspect of this study, you may contact –

anonymously, if you wish -- the School of Public Health Institutional Review Board, University of North Carolina at Chapel Hill, CB # 7400, Chapel Hill, NC 27599-7400, or by phone 919-966-3012. You may call collect.

Thank you for your time and consideration.

- Do you have any questions about anything I have said so far?
- Do you agree to take part in this interview?
- Do you agree to be tape-recorded?

## Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.

### Persons with 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 60 minutes to talk to you about living in Raleigh and your opinions concerning the strengths of Raleigh and the challenges it faces. We are especially interested in learning about the experiences of persons with disabilities living in Raleigh. 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. Because your opinions are important to us, we would like to tape record the discussion to make sure not to miss anything. At any time during the interview, we can turn the tape recorder off at your request.

1. *Start with icebreaker. (ex: tell us 1 interesting thing about yourself...facilitator to start, etc)*
2. *What is it like living in Raleigh? Probe: housing, recreation activities, transportation, employment, schools, community services, access to resources and services*
3. *What do you think life is like for persons with disabilities in Raleigh?*
4. *What services and businesses do you use in the community? (anything they can think of; ex: businesses, social services, government services, profit and non-profit services, advocacy groups, etc)*
5. *What services and businesses do you not use in the community? Probe: Are there any that you cannot use? Why?*
6. *What are service providers like in the community? Probe: attitude, behavior, how do they help you?*
7. *If someone with a disability (or disabilities) moved to Raleigh, what would you tell him or her are the advantages and challenges of living in Raleigh? Probe: accessibility, services, discrimination. How do these affect people's health?*
8. *When there are problems in the community, how are they handled? Probe: accessibility issues, ice storms in the past which caused power outages or limited transportation...how did residents (including those with disabilities) cope?*
9. *How do you think Raleigh serves person with disabilities?*
10. *How do you think Raleigh could better serve persons with disabilities? Probe: if you were in charge of community services, or if you were the mayor, what services would you offer? what programs would you change or cancel?*
11. *Would you consider persons with disabilities in Raleigh to be a "community"? Why/why not? How so/in what way? (be ready to be questioned about the meaning of community; we want to know their ideas and what they think, not our ideas and what we think)*
12. *Is there anything else that you want to tell us about the Raleigh community?*
13. *Are there people in the community who you think it is important for us to talk to about these issues?*
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 A: Interview guides, fact sheets, and recruitment consent forms, cont.

### Community 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 60 minutes to talk to you about living in Raleigh and your opinions concerning the strengths of Raleigh and the challenges it faces. We are especially interested in learning about the experiences of persons with disabilities living in Raleigh. 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. Because your opinions are important to us, we would like to tape record the discussion to make sure not to miss anything. At any time during the interview, we can turn the tape recorder off at your request.

1. *Start with icebreaker. (ex: tell us 1 interesting thing about yourself...facilitator to start, etc)*
2. *What is it like living in Raleigh? Probe: housing, recreation activities, transportation, employment, schools, community services, access to resources and services*
3. *What services and businesses do you use in the community? (anything they can think of; ex: businesses, social services, government services, profit and non-profit services, advocacy groups, etc)*
4. *What services and businesses do you not use in the community? Probe: Why don't you use these services?*
5. *What are service providers like in the community? Probe: attitude, behavior, how do they help you?*
6. *When there are problems in the community, how are they handled? Probe: accessibility issues, ice storms in the past which caused power outages or limited transportation...how did residents (including those with disabilities) cope?*
7. *What do you think life is like for persons with disabilities in Raleigh?*
8. *What do you think are the challenges facing persons with disabilities in Raleigh? Probe: accessibility, services, discrimination. How do these affect people's health?*
9. *How do you think persons with disabilities handle problems in the community? (probe as in #6)*
10. *How do you think Raleigh serves persons with disabilities?*
11. *How do you think Raleigh could better serve persons with disabilities?*
12. *Would you consider persons with disabilities in Raleigh to be a "community"? Why/why not? How so? (be ready to be questioned about the meaning of community; we want to know their ideas and what they think, not our ideas and what we think)*
13. *Is there anything else that you want to tell us about the Raleigh community?*
14. *Are there are the people in the community who you think it is important for us to talk to about these issues?*
15. *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 A: Interview guides, fact sheets, and recruitment consent forms, cont.

### 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 Raleigh and your opinions concerning the strengths of Raleigh and the challenges it faces. We are especially interested in learning about the experiences of persons with disabilities living in Raleigh. 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. Because your opinions are important to us, we would like to tape record the discussion to make sure not to miss anything. At any time during the interview, we can turn the tape recorder off at your request.

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 Raleigh? *Probe: Would you define it as a community?*
6. What would you say are the strengths of the communities you serve?
7. What do you think are the major issues facing persons with disabilities in your community? *Probe: Accessibility, Services, Discrimination . How do these affect people's health?*
8. What are the implications of these issues?
9. What services does your organization provide to address these issues?
10. How do persons with disabilities respond to these issues?
11. If you were in charge of community services for persons with disabilities, what would you do? How would you ensure that persons with disabilities have full access? What if you were in charge of community services for the general population? *Probe: What services would you offer? What programs would you change or cancel?*
12. Have I/we forgotten anything? Is there anything else you would like to say?
13. Would you like to recommend someone else to be interviewed?
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 A: Interview guides, fact sheets, and recruitment consent forms, cont.

### 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 60 minutes to talk to you about living in Raleigh and your opinions concerning the strengths of Raleigh and the challenges it faces. We are especially interested in learning about the experiences of persons with disabilities living in Raleigh. 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. Because your opinions are important to us, we would like to tape record the discussion to make sure not to miss anything. At any time during the interview, we can turn the tape recorder off at your request.

1. *Start with icebreaker. (ex: tell us 1 interesting thing about yourself...facilitator to start, etc)*
2. How long have you lived in Raleigh?
3. Do you currently work in Raleigh? *(maybe probe more for contextual info if they just say yes/no)*
4. How would you describe Raleigh?
5. Describe life in Raleigh for adults.
6. Describe life in Raleigh for adults with disabilities. *Probe: jobs, recreation, hangouts, activities, solving differences*
7. What, if anything, makes you proud about living in Raleigh?
8. How do people support each other in Raleigh?
9. What kinds of programs/services are offered in Raleigh? *(anything they can think of; ex: businesses, social services, government services, profit and non-profit services, advocacy groups, etc); How are services made available to persons with disabilities? Probe: education, recreation*
10. How do you feel about the services available for persons with disabilities? *Probe: positives aspects, challenges, etc.*
11. To what extent are families involved or included in services for persons with disabilities?
12. What do you think are the challenges facing Raleigh? *Probe: growth, development, discrimination*
13. What do you think are the challenges facing persons with disabilities in Raleigh? *Probe: accessibility, services, discrimination. How do these affect people's health?*
14. How do these challenges impact health?
15. What strengths/resources does Raleigh have to help deal with these challenges?
16. If someone were to ask you if Raleigh is a good place to live, how would you respond?
17. If you were mayor, what would you do to improve Raleigh?
18. Would you consider persons with disabilities in Raleigh to be a "community"? Why/why not? How so? *(be ready to be questioned about the meaning of community; we want to know their ideas and what they think, not our ideas and what we think)*
19. Have I/we forgotten anything? Is there anything else you would like to say?
20. Would you like to recommend someone else to be interviewed?
21. 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*

**Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.**

*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 A: Interview guides, fact sheets, and recruitment consent forms, cont.**

### **Focus Group Consent Form/Fact Sheet for Raleigh Community Member/Family Members**

#### **WHAT IS THIS STUDY ABOUT?**

You are invited to take part in a research study, which is a community assessment of the experiences of persons with disabilities, 18 years and older living in Raleigh, North Carolina. The purpose of the study is to better understand the experiences of members of the Raleigh community. You are being asked to take part because we want to gain the perspective of individuals with disabilities, family members, other community members, and service providers on Raleigh's strengths and needs regarding services and supports for people with disabilities.

My name is \_\_\_\_\_ and \_\_\_\_\_ and \_\_\_\_\_ will be assisting in the group today. We are part of a 6-person team from UNC School of Public Health that is conducting a study as part of a class requirement. If you have any questions that we are unable to answer to your satisfaction please contact Darcie Mersereau a graduate student at the UNC or the faculty advisor Eugenia Eng, DrPH.

Darcie Mersereau (919) 966-3919  
UNC School of Public Health  
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Education  
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Chapel Hill, NC 27599-7440

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Dept of Health Behavior and Health  
Education  
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Chapel Hill, NC 27599-7440

#### **WHAT WILL I BE ASKED TO DO?**

You will be asked to take part in a focus group. The focus group is a discussion between all members of the group. I will serve as facilitator and ask questions that we want all members to provide input on and discuss. You will be asked questions about life in Raleigh as it relates to people with disabilities. An example of a general question is, "How would you describe Raleigh?" An example of a more specific question would be, "How do you think Raleigh serves persons with disabilities?" There are no wrong answers or bad ideas, just different opinions. We are looking for points of view, so say what is on your mind. We are interested in your perspective as a community member and/or family member. If you do not feel comfortable answering a question or do not have an opinion, just let us know. You do not have to answer every question.

The focus group will take about 60 minutes of your time. Your participation in the focus group will be one-time only, though you may also attend a community forum in April. At the community forum you can hear and discuss the results of the community research.

If you agree to take part in the focus group we will be recording your responses on a piece of paper. Also, if it is okay with you we would like to tape record the discussion to make sure not to miss anything. Only members of our group will listen to the tapes. The tapes will be erased after our study is over. Anytime during the focus group the tape recorder can be turned off at your request.

#### **WHAT ARE THE RISKS AND BENEFITS OF MY PARTICIPATION?**

## **Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.**

There are few physical, psychological, or social risks associated with participating in this study. The questions for the participants do not include probing of information that might be considered offensive, threatening, or degrading. Focus groups will focus primarily on the strengths, weaknesses, and directions for development for the Raleigh community. No names or identifying information will be attached to focus group data, and the data will be kept in a secure, locked cabinet at the School of Public Health. Though participants of focus groups will remain anonymous, they may know one another. To protect you from any risk of statements being shared outside the group, participants will be asked not to talk to anyone else about what people said during this discussion. You have the option of not answering any question(s) and of turning off the tape recorder at any time. You also have the option of withdrawing from participation of a focus group at any time.

Although you may not experience any direct benefits, your participation may help to make things better in Raleigh over time. 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, it will not change any services you are entitled to.

### **ARE THERE ANY COSTS?**

There are no financial costs for participating in the study. The only cost is your time.

### **WILL I BE PAID?**

You will not be paid for your participation, though there will be refreshments provided at the focus group.

### **SUBJECT'S RIGHTS AND CONFIDENTIALITY**

If you agree to take part in this study, please understand that your participation is voluntary (you do not have to do it). You have the right to withdraw your consent or stop your participation at any time without penalty or question. You have the right to refuse to answer particular questions. During the focus group you may ask that the recording be stopped at any time.

To protect your privacy, any information you provide will remain anonymous. Though your name and address may be collected, it will be recorded separately and will not be used in any way in the research study or linked to your responses. It will only be used for general communications, such as inviting you to attend the community forum.

In this group activity, you do not need to use your real name. You may use a made up name if you wish. You must agree not to tell anything you learn about other people in the group or the details of the discussion.

Identifying information such as age, ethnicity, sex and number of years residing in Raleigh may be obtained during the interview. Such descriptive characteristics are collected only to help summarize our data. When reporting our data all identifying information will be removed so your responses and comments will not be linked to you. The only people with access to all data are the members of the community study team and the faculty advisors. All notes and audiotapes

## **Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.**

containing your interview responses will be stored in a secure, locked cabinet at the School of Public Health and will be destroyed in May 2004 at the conclusion of the study.

If you have any questions or concerns about your rights as a research participant, and/or if you want to withdraw from the study at anytime, please do not hesitate to contact Darcie Mersereau or the faculty advisor Eugenia Eng, DrPH (contact information on page 1 of this form).

This project has been reviewed and approved by the UNC-Chapel Hill School of Public Health Institutional Review Board on Research Involving Human Subjects. 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 School of Public Health Institutional Review Board, University of North Carolina at Chapel Hill, CB # 7400, Chapel Hill, NC 27599-7400, or by phone 919-966-3012. You may call collect.

Thank you for your time and consideration.

- Do you have any questions about anything I have said so far?
- Do you agree to take part in this focus group under these conditions?
- Do you agree to be tape-recorded?

## **Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.**

### **Focus Group Consent Form/Fact Sheet for Person with a Disability**

#### **WHAT IS THIS STUDY ABOUT?**

You are invited to take part in a research study, which is a community study of the experiences of persons with disabilities, 18 years and older living in Raleigh, North Carolina. The purpose of the study is to better understand the experiences of members of the Raleigh community. You are being asked to take part because we want to gain the perspective of individuals with disabilities, family members, other community members, and service providers on Raleigh's strengths and needs regarding services and supports for people with disabilities.

My name is \_\_\_\_\_ and \_\_\_\_\_ and \_\_\_\_\_ will be assisting in the group today. We are part of a 6-person team from UNC School of Public Health that is conducting a study as part of a class requirement. If you have any questions that we are unable to answer to your satisfaction please contact Darcie Mersereau a graduate student at the UNC or the faculty advisor Eugenia Eng, DrPH.

Darcie Mersereau (919) 966-3919  
UNC School of Public Health  
Dept of Health Behavior and Health  
Education  
Campus Box 7440  
Chapel Hill, NC 27599-7440

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

#### **WHAT WILL I BE ASKED TO DO?**

You will be asked to take part in a focus group. The focus group is a discussion between all members of the group. I will serve as the leader and ask questions that we want all members to provide input on and discuss. You will be asked questions about life in Raleigh as it relates to people with disabilities. An example of a general question is, "How would you describe Raleigh?" An example of a more specific question would be, "How do you think Raleigh serves persons with disabilities?" There are no wrong answers or bad ideas, just different opinions. We are looking for points of view, so say what is on your mind. We are interested in your opinion as a person with a disability living in Raleigh. If you do not feel comfortable answering a question or do not have an opinion, just let us know. You do not have to answer every question.

The focus group will take about 60 minutes of your time. You are only being asked to talk with us in a focus group one time, though you may also attend a community forum in April if you wish to hear the results of the community research.

If you agree to take part in the focus group we will be recording your responses on a piece of paper. Also, if it is okay with you we would like to tape record the discussion to make sure not to miss anything. Only members of our group will listen to the tapes. The tapes will be erased after our study is over. Anytime during the focus group the tape recorder can be turned off at your request. Prior to the start of the focus group we will ask your permission to tape record.



## **Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.**

### **WHAT ARE THE RISKS AND BENEFITS OF MY PARTICIPATION?**

There are few physical, psychological, or social risks associated with participating in this study. The questions for the participants do not include probing of information that might be considered offensive, threatening, or degrading. Focus groups will focus primarily on the strengths, weaknesses, and directions for development for the Raleigh community. No names or identifying information will be attached to focus group data, and the data will be kept in a secure, locked cabinet at the School of Public Health. Though participants of focus groups will remain anonymous, they may know one another. To protect you from any risk of statements being shared outside the group, participants will be asked not to talk to anyone else about what people said during this discussion. You have the option of not answering any question(s) and of turning off the tape recorder at any time. You also have the option of withdrawing from participation of a focus group at any time.

Your participation may help to make things better in Raleigh over time, and you may have the direct benefit of having the opportunity to express your opinions. 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, it will not change any services you are entitled to.

### **ARE THERE ANY COSTS?**

There are no financial costs for participating in the study. The only cost is your time.

### **WILL I BE PAID?**

You will not be paid for your participation, though there will be refreshments provided at the focus group.

### **SUBJECT'S RIGHTS AND CONFIDENTIALITY:**

If you agree to take part in this study, please understand that your participation is voluntary (you do not have to do it). You have the right to withdraw your consent or stop your participation at any time without penalty or question. You have the right to refuse to answer particular questions. During the focus group you may ask that the recording be stopped at any time.

To protect your privacy, any information you provide will remain anonymous. Though your name and address may be collected, it will be recorded separately and will not be used in any way in the research study or linked to your responses. It will only be used for general communications, such as inviting you to attend the community forum.

In this group activity, you do not need to reveal your name. You may use a made up name if you wish. You must agree not to tell anything you learn about other people in the group or the details of the discussion.

Personal information such as age, ethnicity, sex and number of years living in Raleigh may be obtained during the interview. This information will only be collected to help organize our results. All identifying information will be removed from the final report so that your responses and comments will not be linked to you. The members of our research team will be the only people with access to all the data. All notes and audiotapes containing your interview responses

## **Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.**

will be stored in a secure, locked cabinet at the School of Public Health and will be destroyed in May 2004 at the end of the study.

If you have any questions or concerns about your rights as a research participant, and/or if you want to withdraw from the study at anytime, please do not hesitate to contact Darcie Mersereau or the faculty advisor Eugenia Eng, DrPH (contact information on page 1 of this form).

This project has been reviewed and approved by the UNC-Chapel Hill School of Public Health Institutional Review Board on Research Involving Human Subjects. 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 School of Public Health Institutional Review Board, University of North Carolina at Chapel Hill, CB # 7400, Chapel Hill, NC 27599-7400, or by phone 919-966-3012. You may call collect.

Thank you for your time and consideration.

- Do you have any questions about anything I have said so far?
- Do you agree to take part in this focus group under these conditions?
- Do you agree to be tape-recorded?

## **Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.**

### **Focus Group Consent Form for Legal Guardian of a Person with a Disability**

#### **WHAT IS THIS STUDY ABOUT?**

We are conducting a community study of the experiences of persons with disabilities 18 years and older living in Raleigh, North Carolina. The purpose of the study is to better understand the experiences of members of the Raleigh community. You are being asked to give participation permission for the person for whom you have guardianship of because we want to gain perspective from various community members including individuals with disabilities on Raleigh's strengths and needs regarding services and supports for people with disabilities.

We are part of a 6-person team from UNC School of Public Health that is conducting a study as part of a class requirement. If you have any questions that we are unable to answer to your satisfaction please contact Darcie Mersereau a graduate student at the UNC or the faculty advisor Eugenia Eng, DrPH.

Darcie Mersereau (919) 966-3919  
UNC School of Public Health  
Dept of Health Behavior and Health  
Education  
Campus Box 7440  
Chapel Hill, NC 27599-7440

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

#### **WHAT WILL I BE ASKED TO DO?**

You will be asked to give permission for the person for whom you have guardianship to take part in a focus group. A focus group is a discussion between all members of the group. A member of the research team will serve as facilitator and ask questions that we want all members to provide input on and discuss. The focus group is made up of questions about life in Raleigh as it relates to people with disabilities. An example of a general question is, "How would you describe Raleigh?" An example of a more specific question would be, "How do you think Raleigh serves persons with disabilities?" There are no wrong answers or bad ideas, just different opinions. We are looking for points of view, so we will encourage all members to say what is on their mind. We are interested in the participant's perspective as a community member with a disability. If he or she does not feel comfortable answering a question or does not have an opinion, he or she can just let us know. He or she does not have to answer every question.

The focus group will take about 60 minutes and participation will be one-time only, though you both may also attend a community forum in April if you wish to hear the results of the community research.

During the discussion we will record responses on a piece of paper. If participants have no objections we would like to tape record the discussion to make sure not to miss anything. Only members of our group will listen to the tapes. The tapes will be erased after our study is over. Anytime during the focus group the tape recorder can be turned off by request. No one has to answer any questions that they are uncomfortable with. Prior to the start of the focus group we

## **Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.**

will ask for permission to tape record.

### **WHAT ARE THE RISKS AND BENEFITS OF PARTICIPATION?**

There are few physical, psychological, or social risks associated with participating in this study. The questions for the participants are not offensive, threatening, or degrading. Focus groups will focus primarily on the strengths, weaknesses, and directions for development for the Raleigh community. No names or identifying information will be attached to focus group data. The data will be kept in a secure, locked cabinet at the School of Public Health. 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 asked not to talk to anyone else about what people said during this discussion. The participant has the option of not answering any question(s) and of turning off the tape recorder at any time. He or she also has the option of withdrawing from participation of a focus group at any time.

His or her participation may help to make things better in Raleigh over time, and he or she may have the direct benefit of having the opportunity to express his or her opinions. Your granting of permission will not influence any of the services you or the person for whom you have guardianship receive or might receive. You can say yes or no to our request; it will not change any services you or the person for whom you have guardianship of are entitled to.

### **WILL THERE BE COSTS?**

There are no financial costs for participating in the study. The only cost is time.

### **WILL THERE BE PAYMENT?**

There is no payment for participation, though there will be refreshments provided at the focus group.

### **SUBJECT'S RIGHTS AND CONFIDENTIALITY:**

If you agree to allow the person you have guardianship over to take part in this study, please understand that his or her participation is voluntary (he or she do not have to do it). You have the right to withdraw your consent or stop his or her participation at any time without penalty or question. He or she will have the right to refuse to answer particular questions. During the focus group he or she may ask that the recording be stopped at any time.

To protect his or her privacy, any information provided by the person you have guardianship over will remain anonymous. Though his or her name and address may be collected, it will be recorded separately and will not be used in any way in the research study or linked to his or her responses. It will only be used to invite you and the person you have guardianship over to attend the community forum.

In this group activity, the person you have guardianship over does not need to use his or her real name. He or she may use a made up name if you wish. He or she must agree not to tell anything he or she learns about other people in the group or the details of the discussion.

**Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.**

Personal information such as age, ethnicity, sex and number of years living in Raleigh may be obtained during the interview. This information will only be collected to help organize our results. All identifying information will be removed from the final report so that responses and comments will not be linked to you or the person you have guardianship over. The members of our research team will be the only people with access to all the data. All notes and audiotapes containing your interview responses will be stored in a secure, locked cabinet at the School of Public Health and will be destroyed in May 2004 at the end of the study.

If you have any questions or concerns about the rights of the person you have guardianship over as a research participant, and/or if you want him or her to withdraw from the study at anytime, please do not hesitate to contact Darcie Mersereau or the faculty advisor Eugenia Eng, DrPH (contact information on page 1 of this form).

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

Thank you for your time and consideration. Please sign this consent form and return by the stated date. Keep the duplicate copy for your records.

I DO give my consent for \_\_\_\_\_ to take part in a focus group as  
Name of person for whom you have guardianship

part of the UNC-Chapel Hill School of Public Health's Community Diagnosis in Raleigh, North Carolina.

Guardian Signature \_\_\_\_\_ Date \_\_\_\_\_

## **Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.**

### **Focus Group Consent Form for Raleigh Service Providers**

#### **WHAT IS THIS STUDY ABOUT?**

You are invited to take part in a research study, which is a community assessment of the experiences of persons with disabilities, 18 years and older living in Raleigh, North Carolina. The purpose of the study is to better understand the experiences of members of the Raleigh community. You are being asked to take part because we want to gain perspective from individuals with disabilities, family members, other community members, and service providers on Raleigh's strengths and needs regarding services and supports for people with disabilities.

My name is \_\_\_\_\_ and \_\_\_\_\_ and \_\_\_\_\_ will be assisting in the group today. We are part of a 6-person team from UNC School of Public Health that is conducting a study as part of a class requirement. If you have any questions that we are unable to answer to your satisfaction please contact Darcie Mersereau a graduate student at the UNC or the faculty advisor Eugenia Eng, DrPH.

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UNC School of Public Health  
Dept of Health Behavior and Health  
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Eugenia Eng (919) 966-3909  
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#### **WHAT WILL I BE ASKED TO DO?**

You will be asked to take part in a focus group. The focus group is a discussion between all members of the group. I will serve as facilitator and ask questions that we want all members to provide input on and discuss. The focus group made up of questions about life in Raleigh as it relates to people with disabilities. An example of a general question is, "How would you describe Raleigh?" An example of a more specific question would be, "How do you think Raleigh serves persons with disabilities?" There are no wrong answers or bad ideas, just different opinions. We are looking for points of view, so say what is on your mind. We are interested in your perspective as a service provider for the community members of Raleigh. If you do not feel comfortable answering a question or do not have an opinion, just let us know. You do not have to answer every question.

The focus group will take about one hour of your time. Your participation in the focus group will be one-time only, though we hope you will attend our community forum in April. At the community forum you can hear the results of the community research.

During the discussion your responses will be recorded on a piece of paper. If you have no objections we would like to tape record the discussion to make sure not to miss anything. Only member of our group will listen to the tapes. The tapes will be erased after our study is over. Anytime during the focus group the tape recorder can be turned off at your request. 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.

## **Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.**

### **WHAT ARE THE RISKS AND BENEFITS OF MY PARTICIPATION?**

There are few physical, psychological, or social risks associated with participating in this study. The questions for the participants do not include probing of information that might be considered offensive, threatening, or degrading. Focus groups will focus primarily on the strengths, weaknesses, and directions for development for the Raleigh community. However, one potential risk may be that if you say any bad things about the community or the services you provide in the community and that information is made known, you may be at risk for losing your job. This information could also affect any political career you may choose to have. We will do the best we can to protect you from this risk by not attaching names or identifying information to focus group data and by storing the data in a secure, locked cabinet at the School of Public Health. Though participants of focus groups will remain anonymous, they may know one another. To protect you from any risk of statements being shared outside the group, participants will be asked not to talk to anyone else about what people said during this discussion. You have the option of not answering any question(s) and of turning off the tape recorder at any time. You also have the option of withdrawing from participation of a focus group at any time.

Although you may not experience any direct benefits, your participation may be beneficial to community improvement efforts by providing useful information that can be used by Raleigh to plan and improve community services available for its residents. 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, it will not change any services you get.

### **ARE THERE ANY COSTS?**

There are no financial costs for participating in the study. The only cost is your time.

### **WILL I BE PAID?**

You will not be paid for your participation, though there will be refreshments provided at the focus group.

### **SUBJECT'S RIGHTS AND CONFIDENTIALITY:**

If you agree to take part in this study, please understand that your participation is voluntary (you do not have to do it). You have the right to withdraw your consent or stop your participation at any time without penalty or question. You have the right to refuse to answer particular questions. During the focus group you may ask that the recording be stopped at any time. We will ask your permission to tape record before the focus group starts.

To protect your privacy, any information you provide will remain anonymous. Though your name and address may be collected, it will be recorded separately and will not be used in any way in the research study or linked to your responses. It will only be used for general communications, such as inviting you to attend the community forum.

In this group activity, you do not need to use your name. You may use a fictitious name if you wish. You must agree not to reveal anything you learn about other subjects from group discussion or other activities.

## **Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.**

Personal information such as age, ethnicity, sex and number of years living in Raleigh may be obtained during the interview. This information will only be collected to help organize our results. All identifying information will be removed from the final report so that your responses and comments will not be linked to you. The members of our research team will be the only people with access to all the data. All notes and audiotapes containing your interview responses will be stored in a secure, locked cabinet at the School of Public Health and will be destroyed in May 2004 at the end of the study.

If you have any questions or concerns about your rights as a research participant, and/or if you want to withdraw from the study at anytime, please do not hesitate to contact Darcie Mersereau or the faculty advisor Eugenia Eng, DrPH (contact information on page 1 of this form).

This project has been reviewed and approved by the UNC-Chapel Hill School of Public Health Institutional Review Board on Research Involving Human Subjects. 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 School of Public Health Institutional Review Board, University of North Carolina at Chapel Hill, CB # 7400, Chapel Hill, NC 27599-7400, or by phone 919-966-3012. You may call collect.

Thank you for your time and consideration.

- Do you have any questions about anything I have said so far?
- Do you agree to take part in this focus group under these conditions?
- Do you agree to be tape-recorded?



**Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.**

**Recruitment Consent Form**

A team of six students from the UNC School of Public Health is conducting a study of the cultural, social, economic, and health experiences of the Raleigh community and the unique experiences of persons with disabilities in the area. They would be interested in contacting you to take part 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. At the time, you can decide to accept or decline their invitation to take part. I will not know whether you decide to take part 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 Darcie Mersereau, a graduate student at the UNC, or the faculty advisor Eugenia Eng, DrPH.

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UNC School of Public Health  
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May I have permission to give your name and contact information to them?

## Appendix A: Interview guides, fact sheets, and recruitment consent forms, cont.

### Recruitment Consent Form \*

A team of six students from the UNC School of Public Health is conducting a study of the cultural, social, economic, and health experiences of the Raleigh community and the unique experiences of persons with mental disabilities, including mild mental retardation and mild mental illness, in the area. They would be interested in contacting you to take part 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. At the time, you can decide to accept or decline their invitation to take part. I will not know whether you decide to take part or not. Regardless of your decision, any services you may use will not be affected in any way. If you have any questions about the study, you can contact Darcie Mersereau, a graduate student at the UNC, or the faculty advisor Eugenia Eng, DrPH.

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UNC School of Public Health  
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May I have permission to give your name and contact information to them?

---

\* This recruitment consent form is intended for the recruitment of persons with mental disabilities and will be used by professional service providers only.

## Appendix B: Interviewee and Focus Group Characteristics

### Interviews

ID	Date Interviewed	Type of Participant*	Gender
1	1/28/04	Person with a disability	Male
2	1/28/04	Service Provider	Female
3	2/6/04	Service Provider	Male
4	2/11/04	Service Provider	Male
5	2/11/04	Service Provider	Male
6	2/13/04	Service Provider	Female
7	2/18/04	Service Provider	Female
8	2/20/04	Service Provider	Female
9	2/20/04	Service Provider	Female
10	2/20/04	Service Provider	Female
11	2/20/04	Person with a disability / Service Provider	Female
12	2/23/04	Service Provider	Female
13	2/25/04	Service Provider	Male
14	2/25/04	Service Provider	Male
15	2/26/04	Service Provider	Female
16	3/15/04	Service Provider / Person with a Disability	Female
17	3/16/04	Person with a disability	Female
18	3/17/04	Person with a disability / Service Provider	Male
19	3/19/04	Person with a disability/ Community Member	Female
20	3/19/04	Person with a disability/Service Provider/Family Member/Community Member	Male
21	3/20/04	Person with a disability	Male
22	3/20/04	Person with a disability	Female
23	3/21/04	Person with a disability/Service Provider	Female
24	3/22/04	Service Provider	Female
25	3/22/04	Service Provider	Female
26	3/24/04	Person with a disability	Female
27	3/24/04	Person with a disability	Female
28	3/25/04	Person with a disability	Male
29	3/26/04	Service Provider	Male
30	4/2/04	Person with a disability/Service Provider	Female
31	4/2/04	Person with a disability	Female
32	4/8/04	Person with a disability / Service Provider	Male

\*Individuals labeled 'Person with a disability' included those individuals who self-identified as having a disability or who had a visible disability. For individuals fitting two categories (e.g. service provider and person with a disability) the guide used in the interview corresponds to the first category listed above, though in some cases questions from two guides were used.

## Appendix B: Interviewee and Focus Group Characteristics

### Focus Groups

ID	Date	Composition of group	Number of Participants
1	3/28/04	Persons with disabilities, caregivers, one service provider	14
2	4/12/04	Persons with disabilities	3

## Appendix C: Secondary Sources

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# Looking for People who live or work in Raleigh!

Come to a Community Forum about issues of concern for people with disabilities in **Raleigh**.



**When:** Monday, April 19, 2004. Food will be provided from 6:00-6:30 pm. The meeting is 6:30-8:30 pm.

**Where:** Hudson Memorial Presbyterian Church.  
4921 Six Forks Road, Raleigh, NC. The building is accessible on the North side and is on Northclift Route #8.

**Topic / Discussion:** Come together to talk about key issues identified by the disability community and people who serve them. The goal is to develop action plans for the Raleigh community.

**Event is free and open to the public!**

Sign language interpreters, Braille, and large-type handouts will be provided. If you need other accommodations, please contact 919-966-3919 by April 12<sup>th</sup>. Childcare provided with advance request.

# Community Forum

For people with disabilities  
in Raleigh

April 19, 2004

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# Agenda

**Welcome and Housekeeping**

**Assessment Background and Agenda**

**Community Assets**

**An Introduction to Themes**

**A Poem**

**(Moving To Break Out Locations**

**Small Group Discussions: Getting to  
Action Steps**

**(Returning From Break Out Locations**

**Reporting of Action Steps**

**Closing**

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# Assets

“Raleigh is a great town. Raleigh is large enough to be exciting and to learn new things and meet new people and small enough to feel that you are an important part of it. It’s a great place to live.”

“Overall, Wake County is the best place in North Carolina for a person with disabilities to live. No holds barred, all hands down. I didn’t say it was the best place in the world. I said it’s the best place in North Carolina.”

“As a whole the city will respond to issues quickly and effectively. There are issues of livability in downtown Raleigh that are being addressed by a coalition of concerned citizens and businesses, and there are very accessible meetings that go on throughout the year that have produced an incredible groundswell of information and demand that the city responds to – creating a city that is livable by people of all ages and abilities.”

“I think there is the beginning of a lot of really good positive services here that need to continue or in some cases need to be improved upon but there is certainly an essence of getting things on the right track and getting this started in that direction in the city of Raleigh. I think it’s for the most part a pretty good disability friendly place to be and the kinds of things that need to be addressed I feel can be worked on. So I think as a community it can only improve.”

---

# Themes

# Housing

**Summary:** Overall, there seems to be a sense that fully accessible and/or visitable housing in the city of Raleigh is neither very available or attainable, nor very affordable for people with disabilities.

**Quotes:**

“There are some available housing for people with disabilities, but we are not there yet. We’ve got so many people with disabilities that have been living on a fixed income and there needs to be more affordable housing...the affordable housing around Raleigh...some of it is in the worst parts of town.”

“...just because they say it’s accessible does not mean that it really is, and what’s accessible for one person is not for another.”

“...the availability of accessible living for people with disabilities...it’s just not really available...accessibility to homes, not only to get into the home, but also within the home itself...is an issue and will continue to be. And I think it will be for some time until there’s a concerted effort....to make it known to state officials that it’s necessary to comply to the state building code to create accessibility in newly constructed buildings.”

# Transportation

**Summary:**

While Raleigh's transit/paratransit situation is perceived as better than that in most cities and is improving, transportation continues to be one of the chief frustrations for people with disabilities, disconnecting them from work, recreation, and contact with others.

**Quotes:**

"And it's really hard... during State Fair time, on a Sunday, don't even try to get a cab. I'm telling ya, don't try because you won't get one, or it will be three hours."

"(Raleigh has) the best paratransit in the state."

"It's very difficult to do anything on the spur of the moment."

"And it is a requirement by CAT to announce each stop, but we have done studies and ridden the CAT buses and the drivers don't do it... they need the cooperation from the drivers and they're not getting it."

"I don't go to church on Sundays because there's no transportation."

"If I had an unlimited budget, I really would need to get nasty with the city and make them, force them, to have all those external speakers on the buses fixed. "

"I did some research. No taxi companies have wheel accessible vans. Contracted companies do, but Yellow Cab, Capital Cab... don't have wheel chair accessible vans."

---

# Employment

**Summary:**

People with disabilities face discrimination when applying for jobs, and as a result there is an extremely high rate of unemployment/underemployment for people with disabilities.

**Quotes:**

“Well employment for people with disabilities is always a challenge because you can go in there...and if the person hasn’t had any experience in dealing with someone with a disability, you are going to be refused the job just because of their preconceived ideas about what you can do or can’t do”

“Since after 22 years of being happily employed I finally got laid off and joined the ranks of the 75% or so of disabled people who are unemployed. That’s a figure that has not changed since the ADA was passed.”

“Also we get nervous having to mention that we are hearing impaired or deaf on a resume or job application. Don’t be surprised, the employer sees that information and immediately our information goes through the shredder, especially in places not familiar with disability or deafness.”

## Communication with Health Care Providers

### **Summary:**

Service providers as well as the general public have a lack of understanding regarding communication issues for people with disabilities (including the use of Braille and assistive devices)—this negatively impacts the health and quality of life for people with disabilities.

### **Quotes:**

“If people send me something in print, I mean, it's a challenge because there's limited resources to getting print translated into speech or Braille.”

“...if someone who is deaf happens to lose power, they have no way to communicate with emergency services.”

“Audio description for the arts in Raleigh exclusively functions in English...we don't have an answer for the non English component although that's certainly something to consider. It's such a growing primary language in Central North Carolina which is our market...so that's something we should consider and we're not addressing it in any particular way”

“...not having access to critical information related to critical health problem is a big concern. For instance if a deaf person ends up in the hospital, some hospitals take forever to get an interpreter. The time in between the doctor or nurses will try to move on without an interpreter, the deaf person feels intimidated or oppressed and tries to cooperate. HEY DONT WANT TO MAKE DOCTOR ANGRY HE IS HOLDING KNIFE AND ABOUT TO OPERATE ON ME!”

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# The Built Environment:

Sidewalks, parking, and buildings in the community

## Summary:

Service providers recognize that the built environment may not be accessible, but both providers and people with disabilities are unclear how to bring about change due to the complicated nature of ADA regulations. It is also felt that Raleigh is not pedestrian friendly due to a lack of curbcuts, inadequate sidewalks, poor parking, and constant construction.

## Quotes:

“I generally make an appointment to schedule things so that I don't need to use the bathroom when I'm out and about...”

“I don't know how many times I've chase her down because a rack of clothing got caught on her power chair...”

“Curb cuts. That's my concern. NC State curb cuts on Hillsborough Street are just ridiculous. The people putting the asphalt down have no idea how to connect the asphalt with the curb cut. Come down curb cut and suddenly [you are] faced with one and a half inches of asphalt.”

“There's...parts of Raleigh, the sidewalk will be on the right hand side, and then I have to cross the street and go to the left hand side because it's not on both sides. So if you have low vision, that's something you want to do (sarcastically), you wanna cross a major highway to get to the other sidewalk. “

“Parking spaces [are] too small for vans and ramps, you have to learn how to park defensively. in such a way that nobody can make the mistake of parking too close to the side that I need to deploy from.”

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# Accessing Services

**Summary:**

Service providers feel that accessing services is difficult because there is no formal network system, whereas people with disabilities generally find services through personal networks.

**Quotes:**

“...understanding where to access the services is difficult...There’s also a big problem with knowing, getting around to the different agencies...”

“There is a lack of coordination among service providers – separate agencies and separate service providers are not talking to each other.”

“when you don’t coordinate all these separate services and get them in place at the same time, people can’t take advantage of them.”

“There is no central, what I would call, database, to where service providers like myself can register. And someone new to the area could look in the phonebook and say ‘Okay, this is who I need’ and they can call up and say ‘This is what I have and the services I need, do you have somebody available?’”

“...they (service providers) have their specific and designated area and in a lot of cases they’re not even aware of other services (provided by the same organization). So it’s really difficult to access them.”

# The Low Road

By Marge Piercy

What can they do to you? Whatever they want.  
They can set you up, they can bust you,  
They can break your fingers, they can burn your brain with electricity,  
blur you with drugs till you can't walk, can't remember, they can take  
your child, wall up your lover.  
They can do anything you can't stop them from doing.  
How can you stop them?  
Alone, you can fight, you can refuse, you can take what revenge you  
can but they roll over you.

But two people fighting back to back can cut through a mob, a snake-  
dancing file can break a cordon, an army can meet an army.

Two people can keep each other sane, can give support, conviction,  
love, massage, hope, sex.

Three people are a delegation, a committee, a wedge.

With four you can play bridge and start an organization.

With six you can rent a whole house, eat pie for dinner with no  
seconds, and hold a fund raising party.

A dozen make a demonstration.

A hundred fill a hall.

A thousand give solidarity and your own newsletter, ten thousand,  
power and your own paper; a hundred thousand, your own media; ten  
million, your own country.

It goes on one at a time;

It starts when you care to act, it starts when you do it again after they  
said no, it starts when you say *We* and know exactly who you mean,  
and each day you mean one more.

---

# Feedback

The team is interested in getting your feedback on the forum. Please email us at [mersereau@unc.edu](mailto:mersereau@unc.edu) or call us at: 966-3919 and let us know your thoughts on:

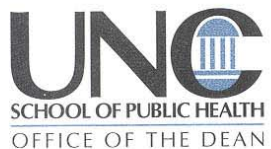
- How you feel about the forum
- Content of the forum
- Accessibility of the event
- Additional comments

The team will be creating a final document that reflects all of the findings of our project, including the action steps you created tonight. The final document will be posted on the web in June 2004, at:

**<http://www.hsl.unc.edu/phpapers/phpapers.cfm>**

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## Appendix E: IRB Approval Letter



TO: Darcie Mersereau  
DEPARTMENT: Health Behavior and Health Education  
ADDRESS: CB # 7440  
DATE: 01/15/2004  
FROM: *Linda S. Adair*  
Linda S. Adair, PhD, Chair  
UNC School of Public Health Institutional Review Board  
IRB NUMBER: 03-2124  
APPROVAL PERIOD: 01/15/2004 through 12/08/2004  
TITLE: Community Diagnosis of Raleigh, North Carolina  
SUBJECT: Full Review Approval Notice--New Protocol

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The IRB reviewed your responses to the clarifications and changes requested after the initial review of your proposal. You have satisfactorily addressed all of the Board's concerns and your project is approved for human subject research and is valid through the expiration date listed 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. IRB00000540.

(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](http://www.sph.unc.edu)

## Appendix F: Codebook:

Codebook:

### *Demographics*

#### *1. Lack of Enforcement of ADA laws*

- 3a. New buildings compliant
- 3b. Old buildings not compliant
- 3c. Privately owned less accessible (church, gym, store)
- 3d. Complicated nature of ADA laws
- 3e. New buildings not compliant
- 3f. Public buildings not accessible

#### *4. View of Persons with disability (PWD)*

- 4a. PWD just like general pop (vary in SES, race, age, etc)
- 4b. Hierarchy/division between disability types
- 4c. Needs are varied
- 4d. Only recognize 'classic disabilities'
- 4e. Growing population

#### *5. Ideas for improvement*

- 5a. Collaborate with PWD/advocacy groups
- 5b. Enhancing awareness /education
  - 5b1. General population
  - 5b2. Service providers
  - 5b3. PWDs
- 5c. Improve transportation
- 5d. Increase Dialogue
- 5c. Housing (affordable and accessible)
- 5e. More funding
- 5f. Support for those who want self-reliance (can rely on own resources)
- 5j. Design programs for older adults with disabilities
- 5h. create database of services
- 5i. more accessible facilities

#### *6. Community*

- 6a. Is a disability community/ feel like part of community
- 6b. No cohesive PWD community
- 6c. Blind community exists
- 6d. Power differentials between different disabilities
- 6e. Spanish speaking PWD have separate community

## 7. *Assets*

- 7a. Strong advocacy in PWD community/active community
- 7b. Vocal
- 7c. Range of support systems
- 7d. strong blind community/good services for the blind
- 7e. Services are well publicized (web accessible, easy to access)
- 7f. Collaboration between agencies
  - 7f1. Resource sharing (including use of networks for marketing)
  - 7f2. Coordination
- 7g. Raleigh is most accessible place in NC
- 7h. Services improving

## 8. *Challenges*

- 8a. Transportation
  - 8a1. Accessibility
  - 8a2. Affordability
  - 8a3. Limited Route and Schedule (no Sunday service, no nighttime service)
  - 8a4. Services not on bus line
- 8b. Built environment
  - 8b1. Facilities not accessible
  - 8b2. Reliance on temporary solutions
  - 8b3. Housing/apt buildings
  - 8b4. Partial accessibility
- 8c. Communication – language/communication barriers (language, large print, Braille)
- 8d. Knowledge
  - 8d1. Lack of knowledge about services and opportunities
  - 8d2. Service not publicized
  - 8d3. Lack of understanding about disability related issues (stereotypes, service animals, paternalistic)
- 8e. Segregation (PWD segregated from general population)/ community integration
- 8f. Lack of collaboration between service providers and agencies
  - 8f1. Poor internal/external collaboration
  - 8f2. Difficult to navigate the system
  - 8f3. Large gaps in services
- 8g. Not enough staff/resources to handle need
- 8h. Hard to enter into system (out of towners, older adults)
- 8i. Poor Quality of Services
- 8j. Services not geared toward all groups (cater to specific groups like youth, specific disability, or those people without disabilities vs. PWD)
- 8k. Employment (underemployed, discrimination in hiring)
- 8l. financial issues (insurance)
- 8m. Institutionalized ableism (complacency, acceptance of poor treatment)
- 8n. Invisible (voiceless)
- 8o. Broad access

## 9. *Implications on health*

- 9a. Emotional well being (low self esteem)

- 9b. Physical well being
- 9c. Mental health affected by exclusion
- 9d. Lower quality of life
- 9e. Negative impact on family member/caretaker physical and mental health
- 9f. No effect on health

#### 10. Raleigh

- 10a. Raleigh as a community
  - 10a1. Collection of many communities
  - 10a2. Maintains small town feel

#### Characteristics of Raleigh

##### 11. ASSETS

- 11a. Resources
  - 11a1. Financially wealthy
  - 11a2. State capitol (access to state services)
- 11b. People
  - 11b1. Diversity
- 11c. Services
  - 11c1. Wide range of services
  - 11c2. Strong recreation/leisure programs
  - 11c3. Strong education system (Good education system for the blind )
- 11d. Quality of Life – (“Good place to live”)
- 11e. Disability friendly
  - 11e1. Many services located in Raleigh
  - 11e2. Good paratransit/ transportation
  - 11e3. Good recreation for PWD
  - 11e4. Accessible museums
  - 11e5. Good reputation for PWD
  - 11e6. Innovative disability programs
  - 11e7. Accessibility in general is good
  - 11e8. Increasing social acceptance of PWD

##### 12. CHALLENGES

- 12a. People
  - 12a1. Diversity (people have different needs)
- 12b. Growth
  - 12b1. Huge population growth
  - 12b2. Pressure to change as a result of growth
  - 12b3. Limited parking downtown
  - 12b4. Traffic
  - 12b5. Difficult to maintaining the same level of services for PWD in the face of population growth and less money
- 12c. Resources



- 12c1. Scarcity of resources/ fighting for resources
- 12d. Employment (bad market, economy)

13. *Technology*

- 13a. Helps PWD (talking devices)
- 13b. Hurts PWD (express checkout)

**Appendix G: Convergent Analysis: Importance and Definition of Issues Identified through Community Members, Service Providers, and Secondary Data Analysis**

<i>Issues</i>	<i>Community Members</i>	<i>Service Providers</i>	<i>Secondary Data Analysis</i>
Housing	<p>-Very important</p> <p>-Accessible housing is not affordable or available; other housing is not visitable</p>	<p>-Important</p> <p>-Not enough affordable, accessible, or visitable housing</p>	<p>-Very important</p> <p>-affordable housing is the number one economic health concern for all in Wake County (12); need for more affordable <i>accessible</i> housing units within the city limits; need to improve accessibility requirements for construction</p>
Transportation	<p>-Very important</p> <p>-Limited bus service during evenings and on Sundays; long and indirect bus routes; bus accessibility not at full capacity; insensitive bus drivers; low affordability of private vehicles; transportation impacts work, recreational, and social opportunities</p>	<p>-Very important</p> <p>-Transportation is a barrier to providing services; which could impact health of clients; service is expensive, limited, and not developed to ensure pedestrian safety; bus system is confusing and lacks technological advancements</p>	<p>-Important</p> <p>-Raleigh’s growth puts more vehicles on the road; public transportation is a long ride to work and is barrier to accessing health care; limited evening and Sunday bus service</p>
The Built Environment	<p>-Important</p> <p>-Partially or entirely inaccessible sidewalks, parking areas, bathrooms and other building areas, schools, stores, doctor’s offices; loss of pedestrian friendliness</p>	<p>-Important</p> <p>-Older and private facilities are least accessible; focus on building codes; lack of ADA compliance and enforcement; difficult parking</p>	<p>-Not very important</p> <p>-Stadium-style seating in theaters is often inaccessible for people with disabilities</p>

**Appendix G: Convergent Analysis: Importance and Definition of Issues Identified through Community Members, Service Providers, and Secondary Data Analysis**

<i>Issues</i>	<i>Community Members</i>	<i>Service Providers</i>	<i>Secondary Data Analysis</i>
Communication	<p>-Important</p> <p>-lack of knowledge among service providers about accessible communication; impacts on health, education, and the quality of life for people with disabilities; communication barriers vary by disability type (need for ASL interpreters, TTY services, Braille materials).</p>	<p>-Not very important</p> <p>-Language barriers (mainly Spanish/English) affect provision of services</p>	<p>-Not very important</p> <p>-None explicitly significant... (Inferred: communication may be related to people with disabilities being less likely to seek preventative care and more likely to report dissatisfaction with life and less emotional support (32)</p>
Employment	<p>-Important</p> <p>-Unemployment and underemployment; employment not congruent with education level obtained; economy's impact on employment; transportation to employment; fear of loss of benefits if employed</p>	<p>-Important</p> <p>-Job discrimination; attitudes of persons with disabilities hindering job prospects; services to help people with disabilities, such as financial assistance for those unable to work, job placement and job coaching assistance; limited bus service to work</p>	<p>-Very important</p> <p>-Very high unemployment rates for persons with disabilities, aged 21-64, in Raleigh: 30% of males and 37% of females, 36% of African American males and 59% of Hispanic females with disabilities in this age group are unemployed (16)</p>
Access to Services	<p>-Important</p> <p>-Lack of knowledge about available services but reliance on personal networks to find them; lack of collaboration between and coordination among service agencies</p>	<p>-Important</p> <p>-Lack of collaboration/ coordination between service providers despite good communication; lack of single directory for referring clients to services; lack of knowledge about services among persons with disabilities</p>	<p>Important-</p> <p>-Budget limitations have restricted availability of services; planned closing of Dorothea Dix Hospital</p>

## Appendix H: Data Codes and Frequencies

Codes	Community Members	Service Providers	Totals
<b>Accessing Services</b>	<b>37</b>	<b>45</b>	<b>82</b>
<i>Services improving</i>	6	4	10
<i>Lack of knowledge about services</i>	4	11	15
<i>Collaboration among service providers</i>	6	14	20
<i>Poor quality of services</i>	5	2	7
<i>Wide range of services</i>	12	7	19
<i>Services cater to specific groups</i>	4	7	11
<b>Built Environment</b>	<b>32</b>	<b>19</b>	<b>51</b>
<i>Facilities not accessible</i>	12	6	18
<i>Old buildings and new buildings</i>	8	5	13
<i>Private and public facilities</i>	8	3	11
<i>Partial accessibility/temporary solutions</i>	4	5	9
<b>Communication</b>	<b>7</b>	<b>8</b>	<b>15</b>
<b>Community</b>	<b>17</b>	<b>9</b>	<b>26</b>
<i>Cross-disability community</i>	7	1	8
<i>Subcommunities by disability type/ no cohesive community</i>	10	8	18
<b>Diversity</b>	<b>3</b>	<b>3</b>	<b>6</b>
<b>Education</b>	<b>5</b>	<b>2</b>	<b>7</b>
<b>Financial Issues</b>	<b>4</b>	<b>7</b>	<b>11</b>
<b>Growth</b>	<b>3</b>	<b>11</b>	<b>14</b>
<b>Employment</b>	<b>5</b>	<b>12</b>	<b>17</b>

Note: The shaded row headings are codes. The unshaded row headings are prominent subcodes. Codes appearing more than 15 times were brought to the Community Forum Planning Committee for prioritized for discussion and saliency in the community according to importance and changeability.

## **Appendix I: Small Group Discussion Techniques**

### **Forcefield Analysis**

Forcefield 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 that can be lessened or helping forces that can be strengthened to help create the change.

Forcefield 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 and hindering forces 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.

## **Appendix I: Small Group Discussion Techniques**

### **SHOWED**

SHOWED is a small group discussion technique that is intended to begin with an understanding of the underlying causes of a situation and in action steps. It is a useful technique when the topic of discussion hasn't been addressed by group members previously and when the root causes of the problem have not been articulated.

#### **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.

#### **SHOWED Questions:**

1. S (SEE): What do you see in this picture? What words or phrases in this story stood out to you?
2. H (Happening): What is happening? How do characters in this story feel?
3. O (Our): How does this relate to our lives? Is this common? Have you experienced this?
4. W (Why): What causes this? Who benefits when this happens? Who loses?
5. E (Evaluation): How are we part of the problem? How can we be part of the solution?
6. D (Do): What can we do about this? What steps can the people here right now take?

## **Appendix I: Small Group Discussion Techniques**

### **ORID**

ORID is a small group discussion technique that is intended to begin with an understanding of a situation and 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.

#### **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.

#### **ORID Questions:**

1. O (Objective): What do you see in this picture? What words or phrases in this story stood out to you?
2. R (Reflective): What was your first response? How did you feel when that happened?
3. I (Interpretive): What is this poem about? What were the most significant events? What issues does this dialogue bring up for you?
4. D (Decisional): What change is needed? What can we do here about these issues? What actions can we take? What should be our first step?



## **Appendix J**

The Raleigh Action Oriented Community Diagnosis Team wishes to thank the following organizations and businesses for their generous donations to the Raleigh Community Forum on April 19<sup>th</sup>, 2004.

Applebee's Restaurant

Ben & Jerry's

Chapel Hill Subway

Chili's Restaurant

Cold Stone Creamery

Games Galore

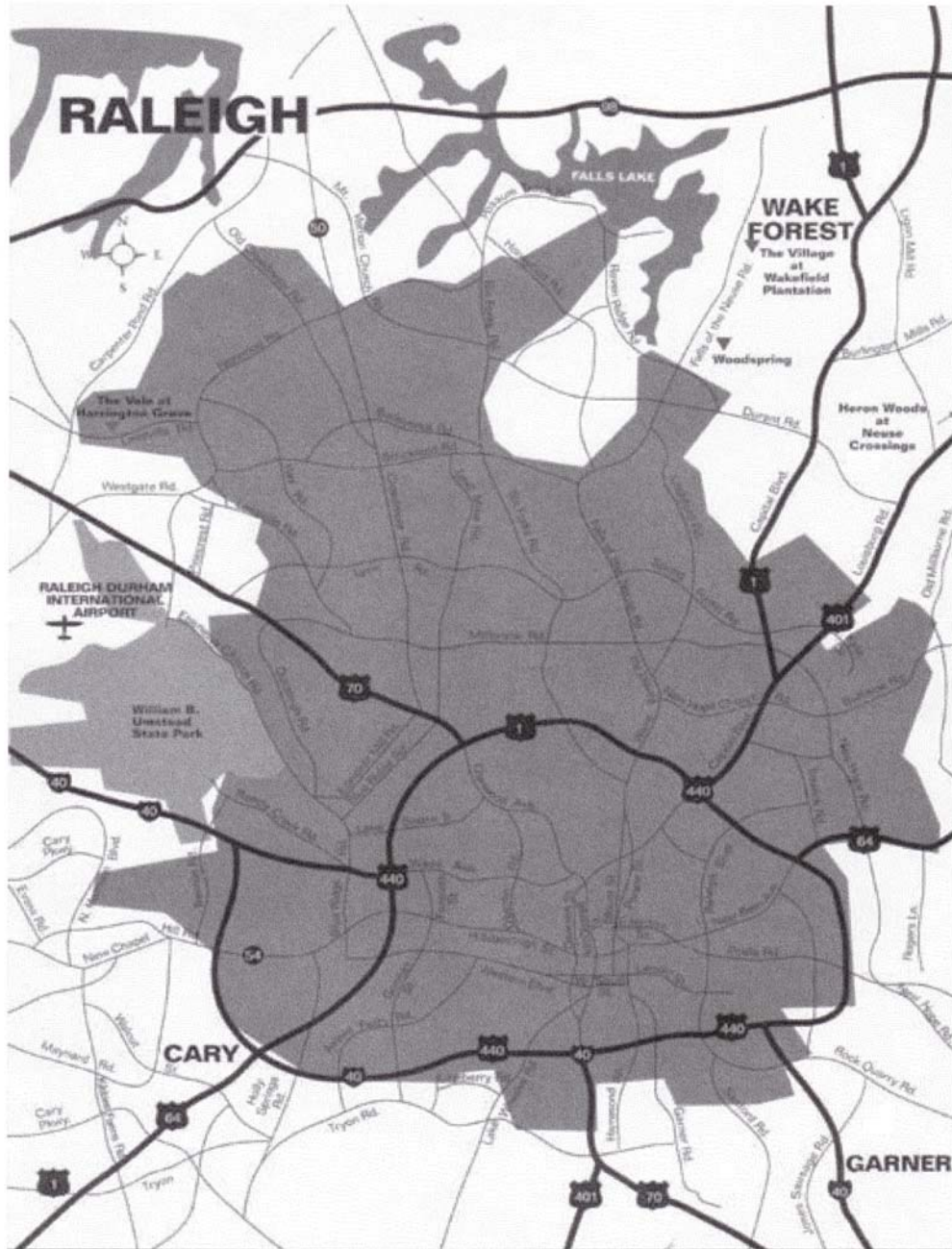
Harris Teeter

Kroger

Lowe's Foods

## Appendix K: Maps of Raleigh

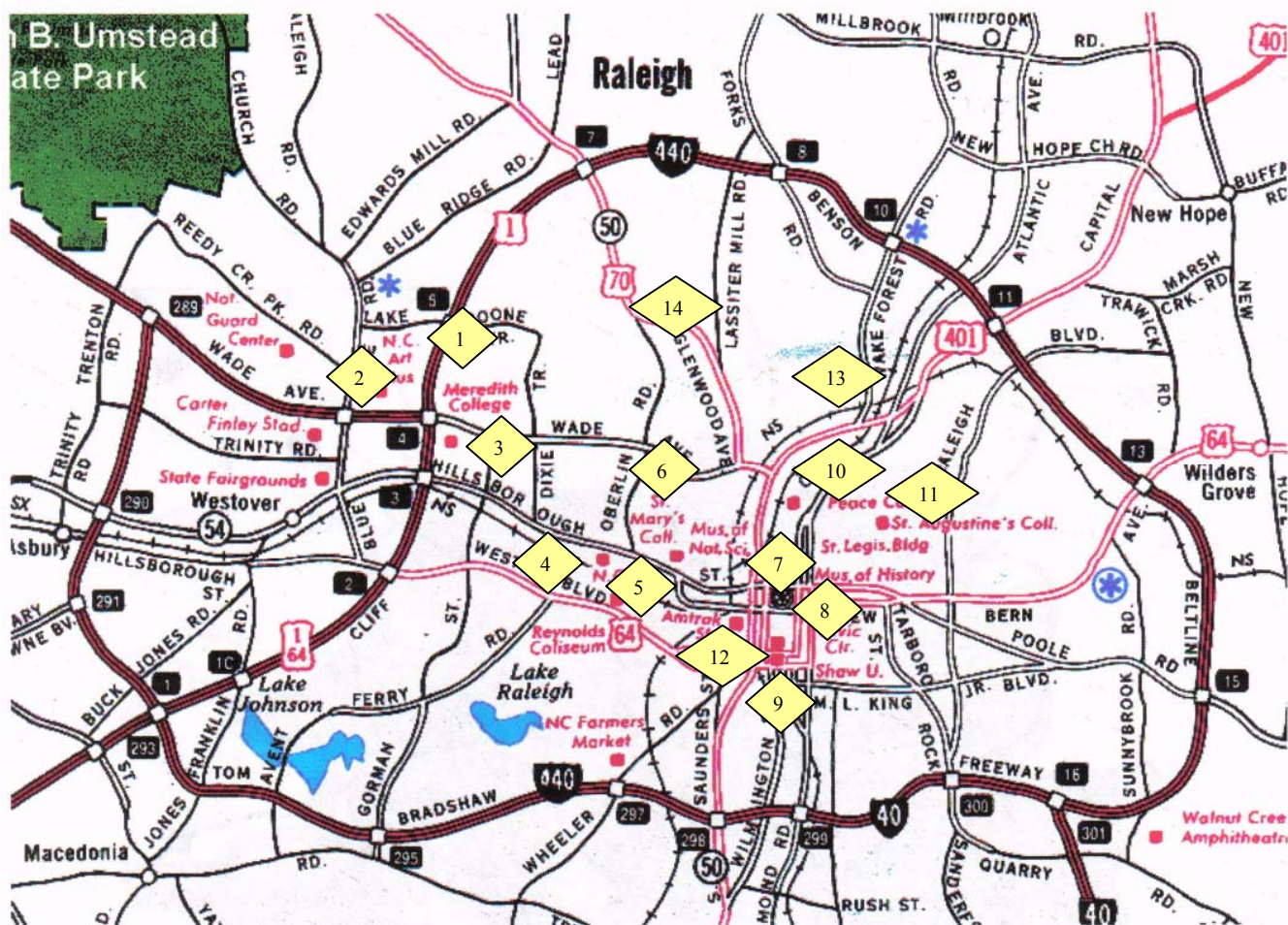
**Map 1:** Raleigh City Limits, including the Beltline



Dark shaded area represents city of Raleigh within Wake County. The loop (I-440) towards the southern part of Raleigh is the Beltline, within which most of the AOCD process was focused.

## Appendix K: Maps of Raleigh

**Map 2:** Landmarks and Sites from Windshield Tour\* of Raleigh (Mostly Inside Beltline)



Key:

1. Lake Boone Trail, Meredith Woods area (near Multiple Sclerosis Easter Seals building)
2. Ridge Road and Ridgewood Shopping Center area
3. Meredith College area, Wade Avenue

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\* These sites represent those from the windshield tour of Raleigh, very close to the onset of the team's AOCD work; while these were the main areas seen by the team, observations were by no means limited to these areas only. Other sites around Raleigh (both inside and outside the Beltline) were observed by the team at later points throughout the AOCD process.

4. Hillsborough Street area: North Carolina State University; Caterpillar machine company (being phased out or area); Small business; University Towers; Pullen Park; Small inns/four-star; upscale motels (Velvet Cloak, Brownstone); IHOP; Apartments/houses; Central YMCA
5. Ashe Street area: Pullen Park entrance; Governor Morehead School for the Blind; Central Prison (men's maximum security prison)
6. Cameron Village area: Fresh Market; Office for Governor's Advisory Council for People Living with Disabilities; US Post Office; Stores/retail shops; private businesses; professional offices; Public Library; also St. Mary's Street and St. Mary's College
7. Downtown Capital Area and Business Areas: City Hall (site of Raleigh Mayor's Committee Meeting for People with Disability); Independent Living Center/Vocational Rehabilitation Building (site of UDA organizational meetings); Capital Building; Green spaces; NC Museum of History; Legislative Building; Visitor's center; Governor's Mansion (at intersection of Blount and Jones Streets); Peace Street, Krispy Kreme; Person Street, old buildings/businesses, nested between capital and Oakwood districts; Fayetteville Street Mall; More Square City Bus Terminal; More Square Park; City market; Exploris Museum and Middles School (magnet school), with IMAX; More Square Museum Middle School (magnet school); Pubs, restaurants, salons, barber shops, tattoo shops, small old business buildings; Artspace; Founder's Row condos; newly constructed Hillsborough Bridge (most expensive bridge construction in NC to date, under construction and blocked off for 2 years); City prison and public safety center; BTI Performance Center (Raleigh Memorial Auditorium); Small free clinic
8. Historic Oakwood area, behind Governor's mansion, across Peace St. at Jones and Person Streets: private homes; churches, few shops/cafes
9. Shaw University area
10. Peace College area...Mordecai Working Plantation
11. St. Augustine's College area
12. Warehouse District area: restaurants; Jillian's; Bars/food places; Dillon Supply Steel Company; Printing shops; cable access TV station; government offices; News and Observer Newspaper office
13. Wake Forest Road area, with NC Council on Developmental Disability office nearby (but moving soon to new location) and Capital Boulevard (Hwy 1): Shelters; Outreach places; NC Library for the Blind and Physically Handicapped
14. Glenwood Avenue area: Five Points area; community park; commercial places, pubs, restaurants, industrial businesses

