People with Disabilities

"Progress is too slow, and the gaps are still too large. Looking back four years, or ten years . . . we see Americans with disabilities heading in the right direction. But people with disabilities remain pervasively disadvantaged. Our goal of full participation is a dream deferred. I hope that the findings . . .will inspire legislators, public officials, and the American people to rededicate themselves to this goal."

Alan A. Reich, 2004[1]

One in five Americans, 49.7 million people, are living with some type of long-lasting condition or disability.[2] While there is no one, universally accepted definition of "disability," for the purposes of this chapter, the sources cited refer to disability as a "condition," usually sensory, physical or mental, that limits daily living or the independence of the individual. People with disabilities face unique challenges, overcoming environmental, social, and emotional barriers to maintain their health and a healthy lifestyle. They are dependent upon community commitment to identify and change those barriers. In Louisiana, 880,047 people ages 5 and older (28 percent) have some kind of a disability. **In St. John the Baptist Parish, it is estimated that 6,682 people ages 5 and older (17 percent) have a disability.**[3]

DID YOU KNOW?

Under the Americans for Disabilities Act (ADA), a person with a disability is someone with a physical or mental impairment which substantially limits one or more activities of daily living (ADL), or someone with a history of such impairment.

Council of Better Business Bureau's Foundation, 1992

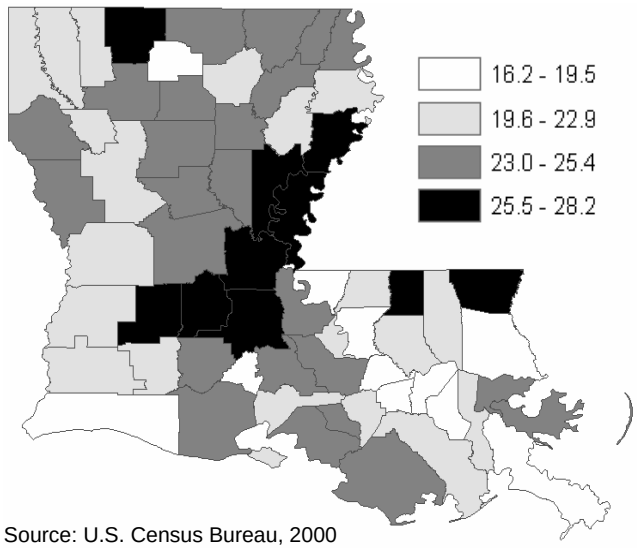
There are many kinds and causes of disabilities. Some are visible, such as spinal cord injuries, while others, such as heart disease, deafness or diabetes are not. Disabilities can be the result of an accident, or can be brought on by chronic disease or simply by becoming frail with age. Interventions, treatment, immunization programs, and safe-behavior practices aimed at individuals, families, and communities can reduce the incidence or impact of disabilities. Medical screenings and treatment can prevent mental retardation caused by rubella, kernicterus, or lead poisoning. Providing substance abuse treatment for a pregnant woman with a history of alcohol abuse is an example of an intervention that can prevent a disability (fetal alcohol syndrome). Accidental injury can be prevented by the use and proper installation of child safety seats, wearing a seat belt, a motorcycle helmet, or practicing and monitoring work-site safety. Preventing disabilities is discussed in the other chapters.

This chapter discusses living with a disability. The first sections of this chapter look at community issues and barriers facing individuals with disabilities. Later sections discuss the scope and magnitude of the populations with disabilities within the parish, the services available, and possible community actions to improve inclusiveness. Included in this chapter is a discussion of the elderly population and related issues. The following indicators are presented:

- Prevalence of disability by race, sex, age and type of disability
- Disparities in employment, earnings, and poverty
- Estimated rate of growth in population 65 and older, percent living in a nursing facility, percent raising their grandchildren

The statewide distribution of the prevalence of disabilities by parish gives community leaders and planners a visual representation of the scope of disability in their area as compared to the rest of the state. Who are these people, what kinds of disabilities do they have, what do they need? The information in this chapter will help community leaders find the answers to these questions.

Percent of Population Reporting a Disability
(Non-institutionalized people 5 years and older)



Source: U.S. Census Bureau, 2000

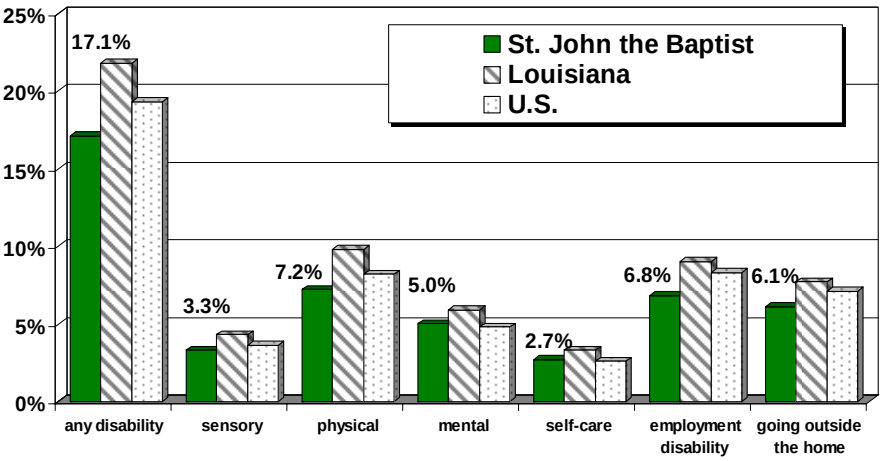
Understanding Census Disability Data—the 2000 Census gathered disability data from the non-institutionalized (those not in facilities such as nursing homes, mental hospitals, etc.) civilian population aged 5 and older from two specific questions with multiple parts on the long form. One question centered on sensory disability and on conditions restricting physical activities while the second question concentrated on a person's difficulty to perform certain activities due to a physical, mental, or emotional condition. The questions on disability were self-reported and were not mutually exclusive, allowing a respondent to report more than one disability and more than one effect.

Prevalence of Disabilities in Your Community

This section will focus on the magnitude, types, and demographics of disabilities in the parish. Census data combined with other data sources will help to define the scope of disability in the community. Community leaders and program providers should use this information as a beginning point to address needs of their citizens with disabilities.

Persons with Disabilities Ages 5 Years and Older	
St. John the Baptist Parish	
Total Persons with a Disability	**6,682**
By Disability Type*	
Sensory	1,279
Physical	2,833
Mental	1,952
Self-care	1,071
Employment disability	2,661
Difficulty going outside the home	2,385

Prevalence of Disability Among Persons 5 years and Older by Disability Type*
(as a percent of total population 5 and older)



Source: U.S. Bureau of the Census, Census 2000 **Disability types are not mutually exclusive*

In the United States:

•The two racial groups reporting the highest disability rate of 243.3 per 1,000 population were Black and American Indian/Alaska Native.

•More males than females report a disability. Among people with disabilities in the 5 to 15 year age group, nearly two-thirds were boys. Only in the 65 and older age group are disability rates for women higher than they are for men.

•Disability rates increased with age; people 65 years and older reported a disability over two times the rate for people 16 to 64 years.[4]

Disability Prevalence by Race, Age and Sex
Rate per 1,000 Population

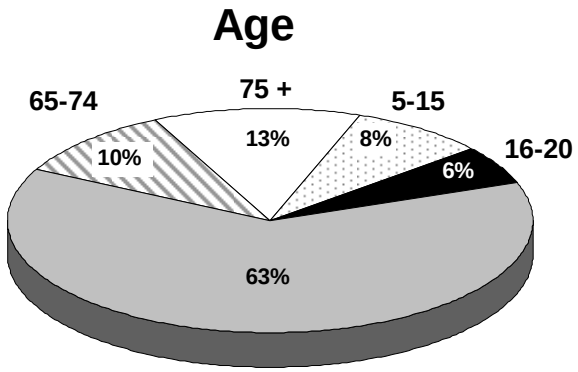
	St. John the Baptist	Louisiana	U.S.
All Persons 5 and Older	170.8	217.5	193.4
White	163.5	205.7	185.3
Black	179.5	242.0	243.3
Other	173.4	217.9	195.7
Male	171.0	224.0	196.1
Female	170.6	211.7	190.9
5-15 Years	67.1	69.7	57.9
16-20 Years	106.1	144.2	132.9
21-65 Years	176.5	221.1	192.0
65-74 Years	351.4	387.3	322.7
75 Years and Older	592.9	606.6	535.9

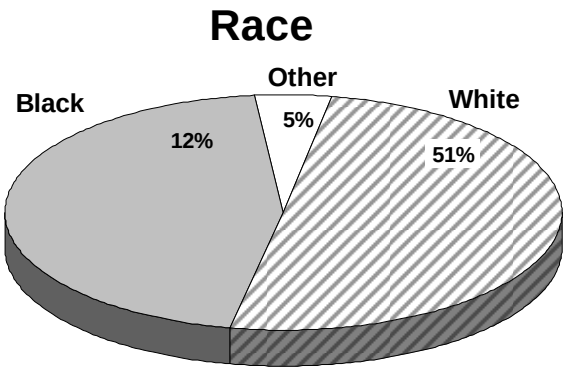
Source: U. S. Census 2000, QT-P21 Summary File 3-Sample Data

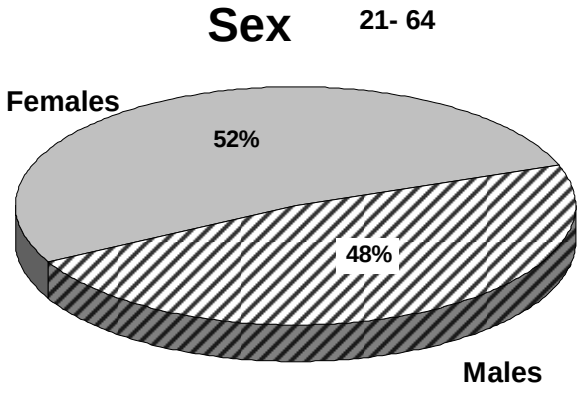
Demographic Composition of People with Disabilities

While people with disabilities represent all racial, ethnic, and social-economic groups, differences exist within gender, races and age groups. By looking at these sub-populations, we can get a better understanding of differences that will help communities target solutions. The U.S. Census Bureau does not recommend comparing Census 2000 with Census 1990, but has used the data to identify trends among specific populations.

Demographic Composition of People with Disabilities
by Age, Race and Sex
St. John the Baptist Parish, 2000







Source: U.S. Bureau of the Census, Census 2000

Disability by Age Group

Census 2000 gathered disability data on people ages five and older. Information on birth to four presented in this section comes from the Louisiana Department of Health and Hospitals, Children's Special Health Services programs. Because census data is gathered by age groups and because disability characteristics, services, and supports required change with age, this section will address prevalence data by age groups.

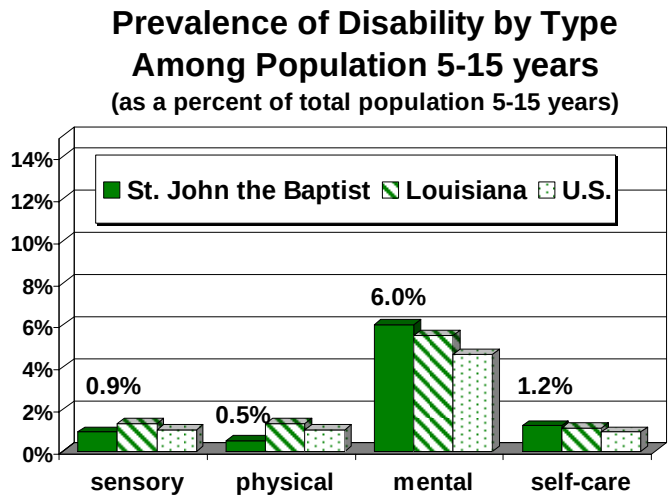
Children and Adolescents: Birth to 20 Years

23.2% of Louisiana households have at least one child with a special health care need.

The 2001 National Survey on Children with Special Health Care Needs provides information about Louisiana children with special health care needs, ages 0-17 years. Accordingly, Louisiana ranks as the second-highest of all the states for children with special health care needs with 16 percent of Louisiana children having special health care needs. Survey data also indicates that 11.4 percent of those are birth to 5 years old, 20.1 percent of these children are uninsured at some point during the year. In addition, 23.2 percent of Louisiana households have at least one child with a special health care need with 85.5 percent of the families indicating that their child received SSI, compared to the national survey response of 70.7 percent.[5] The prevalence of disabilities among children in the state coupled with the high rate of children with special needs who are uninsured indicate a tremendous need for health care services and resources for children with special health care needs.[6]

Infants and Toddlers: Data on disabilities in the general population under 5 years of age is limited. However, program participation data from the EarlySteps Program can be used as a general indicator of the prevalence of disabilities in this age group. EarlySteps, under Children's Special Health Services, Department of Health and Hospitals, Office of Public Health, provides services to infants and toddlers (birth to 3 years) with medical conditions likely to cause disability or developmental delays, or with a physical, cognitive, social and emotional, adaptive, or communication delay. As of July 01, 2004, there were 4,330 children (1.7 percent) in Louisiana receiving EarlySteps services.[7] The Department of Education estimates that approximately 5,850 children (2.3 percent) may be eligible for EarlySteps services in Louisiana.[8]

5-15 Years: For every 1,000 children ages 5-15 in St. John the Baptist Parish, it is estimated that 67 have a disability. This contrasts to almost 58 in 1,000 for the United States and nearly 70 in 1,000 for Louisiana.[9] The most noticeable factor of disability in this age group is the high percentage of people reporting a mental disability. This trend is prevalent in both the U. S. and Louisiana, where according to Census 2000, nearly 8 out of 10 children who report a disability report a mental disability (difficulty in learning, remembering or concentrating). This is greater than any of the other reported disabilities in this age group.[10] One study attributes this to two factors, increased birth and survival rates among low birth weight infants and increased diagnosis of Attention Deficit/Hyperactivity and asthma.[11]

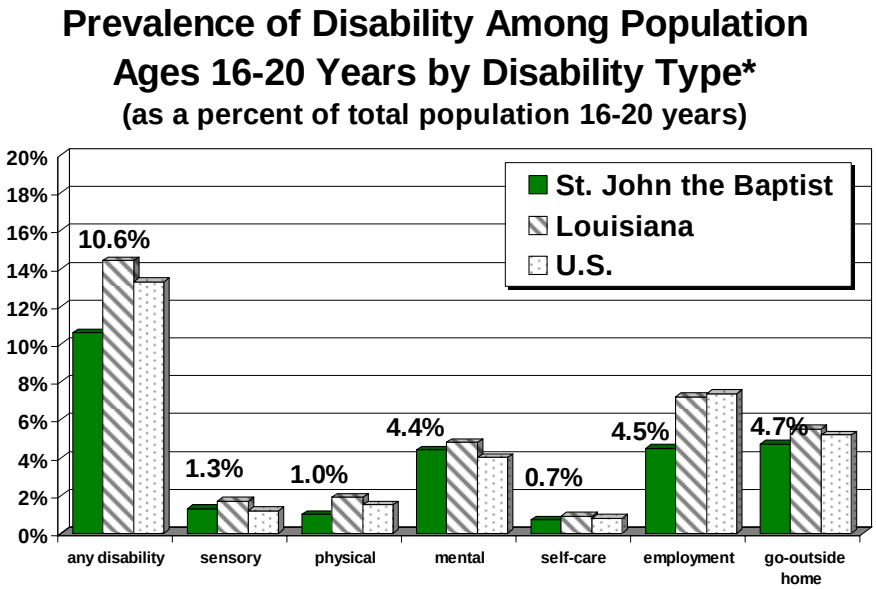


Persons with Disabilities Ages 5-15 Years	
St. John the Baptist Parish	
Total Persons with a Disability	**561**
By Type of Disability*	
Sensory	76
Physical	43
Mental	506
Self-care	102

Source: U.S. Bureau of the Census, Census 2000
**Disability types are not mutually exclusive*

Special Education data from the Louisiana Department of Education (DOE) provides another perspective of the prevalence of children with disabilities in your parish. Included in the school systems' definition for "disability" are specific learning disabilities (ADD for example), speech or language impairments, autism, deaf and hard of hearing, mental disabilities (behavior disorders for example), and developmental delays. According to DOE, for the 2003-2004 school year 13.5 percent of the public school children in Louisiana aged 3-21 were children with disabilities. **Of the 6,431 students in public schools in St. John the Baptist Parish, 18.0 percent (1,158) were children with disabilities**.[12]

16-20 Years: **In St. John the Baptist Parish, it is estimated that 106 out of 1,000 people 16 to 20 years of age report a disability.** This compares to almost 133 in 1,000 for the United States and nearly 144 in 1,000 for Louisiana.[13] The prevalence of disability for this age group is over two times the rate for the 5-15 age groups. While mental disability is the largest reported disability, the prevalence in the U.S. has declined from 8 in 10 in the 5-15 population to just less than 3 in 10 in the 16-20 population.[14] It is important to understand that older adolescents with disabilities have the same aspirations and desires as all teens but they have the additional challenges of being different, communication barriers, and independence issues. Getting an education and job training are essential to getting and maintaining independence for this age group.



Persons with Disabilities Ages 16-20 Years	
St. John the Baptist Parish	
Total Persons with a Disability	**368**
By Type of Disability*	
Sensory	44
Physical	33
Mental	153
Self-care	25
Employment disability	156
Difficulty going outside the home	164

Source: U.S. Bureau of the Census, Census 2000
**Disability types are not mutually exclusive*

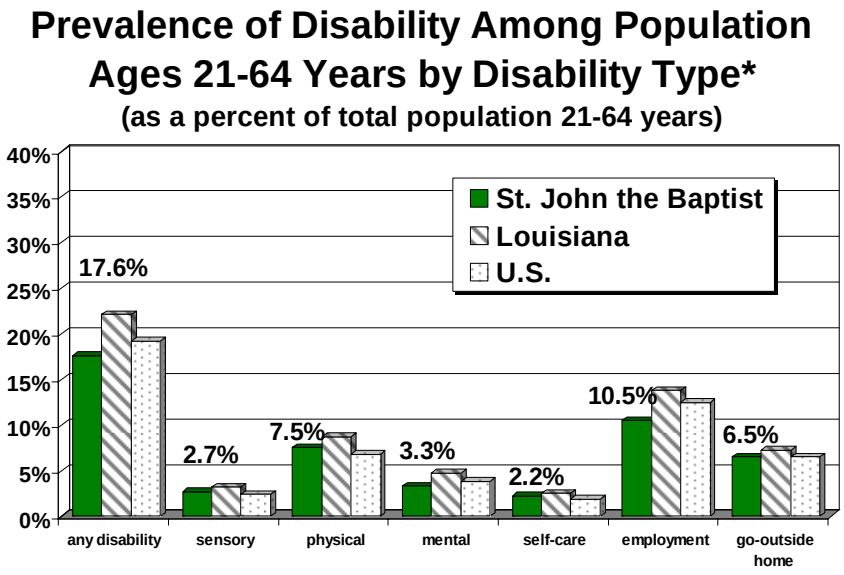
Census 2000 asked respondents in this age group to report on the effects of having a disability on going-outside-the-home and on employment. **In St. John the Baptist Parish of the people 16-20 years of age who report a disability, 164 report a go-outside-the-home disability and 156 report an employment disability.**[15] This information, combined with Louisiana Department of Education (DOE) exit data, gives a clear picture of the need for specialized services for this transitional age group. DOE reported that for the 2003-2004 school year, of Louisiana students ages 14-21 years with disabilities, only one in five (18.9 percent) received a high school diploma, one in four (24 percent) dropped out, and one in twenty (5.3 percent) received some form of skills, activity certificate, or GED.[16] The big challenge for educators, planners, community leaders, and schools is preparing this population for life as an adult with a disability.

The Working Population: 21-64 Years

For every 1,000 adults ages 21-64 in St. John the Baptist Parish, it is estimated that 177 have a disability. This compares to 192 in 1,000 for the United States and 221 in 1,000 for Louisiana.[17] For the 21-64 age groups in both Louisiana and the U.S., the most reported disabilities are physical disability, followed by mental disability.[18] Census 2000 gathered additional employment information on this age group, reporting the percent of the population employed with a disability by disability type. The ability to work affects the economic status of the individual and/or the family and contributes to the overall well-being of people with disabilities. Looking at people who report a disability and who are employed is an indication of job opportunities available for individuals with disabilities.

Persons with Disabilities Ages 21-64 Years	
St. John the Baptist Parish	
Total Persons with a Disability	**4,220**
By Type of Disability*	
Sensory	647
Physical	1,783
Mental	790
Self-care	520
Employment disability	2,505
Difficulty going outside the home	1,546

Source: U.S. Bureau of the Census, Census 2000
**Disability types are not mutually exclusive*



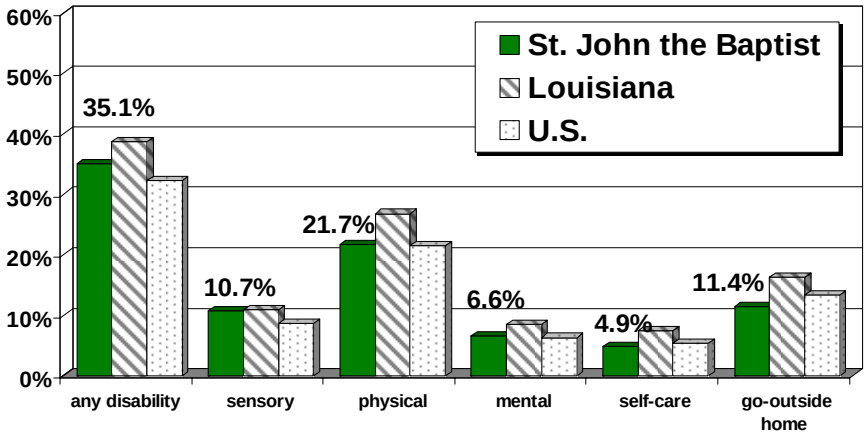
The Elderly: 65 and Older

Aging is another cause of disability; increased frailty causes bones to break easily and chronic disease can limit mobility, sight, hearing or clarity of thought. **In St. John the Baptist Parish, for the 65 and older population, 454 people in 1,000 report a disability compared to the state rate of 481 and the United States rate of 420**.[19] Physical disabilities are the leading type of disability in the elderly population. The high rates of physical disability intensify and compound the problem of going outside the home.

Comparing disability rates for the 75 and older population to the 65-74 population shows the effect of aging on disability**. In St. John the Baptist Parish, it is estimated that 351 people out of 1,000 ages 65-74 years report a disability, compared with 593 people ages 75 and older.** In the United States the prevalence rate is nearly 323 out of 1,000 for ages 65-74 and nearly 536 for ages 75 and older. In Louisiana, the rate is just over 387 for 65-74 years and nearly 607 for 75 and older.[20]

Prevalence of Disability Among Population Ages 65-74 Years by Disability Type*

(as a percent of total population 65-74 years)



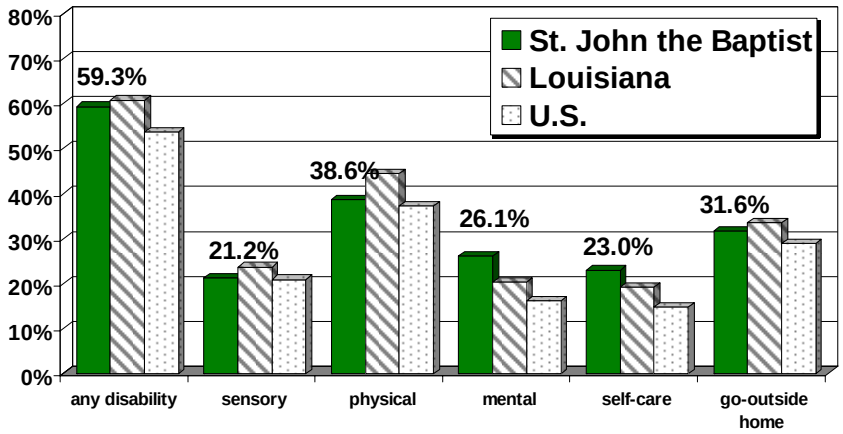
Persons with Disabilities Ages 65-74 Years	
St. John the Baptist Parish	
Total Persons with a Disability	**681**
By Type of Disability	
Sensory	208
Physical	420
Mental	128
Self-care	94
Difficulty going outside the home	221

Source: U.S. Bureau of the Census, Census 2000
**Disability types are not mutually exclusive*

In the 75 and older age group, the percentage of people needing self- care assistance increased at both the state and national level. Individuals who report being unable to care for themselves will need access to in-home services and possibly long-term care facilities. Community leaders and program planners should be aware of the increasing burden on families and caregivers as the need for help increases in the elderly population.

Prevalence of Disability Among Population Ages 75 Years and Older by Disability Type*

(as a percent of total population 75 years and older)



Persons with Disabilities Ages 75 Years and Older	
St. John the Baptist Parish	
Total Persons with a Disability	**852**
By Type of Disability*	
Sensory	304
Physical	554
Mental	375
Self-care	330
Difficulty going outside the home	454

Source: U.S. Bureau of the Census, Census 2000
**Disability types are not mutually exclusive*

Other Impacts of Aging

Not all of the elderly populations in your community are people with disabilities. However, some of the issues and needs confronting people with disabilities are common to the elderly, e.g., the need for long-term care and independence. These issues combined with the growing elderly population are challenges that the community must be prepared to meet. From 1950 to 2000, the proportion of the United States population 75 years and older increased from 3 percent of the population to 6 percent of the population.[21] It is estimated that by 2010, 13.9 percent of the population of the state will be 65 years and older.[22]

Census 2000 counted 516,929 Louisiana citizens aged 65 and older. They make up 11.6 percent of the state's population. **In St. John the Baptist Parish, 3,356 people are 65 and older, making up 7.8 percent of the parish population; 5 percent are 65-74 years old, 2.5 percent are 75-85 years old and .8 percent are 85 years and older.**[23] Health, economic and social needs increase with age, and Louisiana's elderly population is growing and the number of those living well into their eighties and nineties is increasing. It will be necessary to increase the services provided to this population.

Living Arrangements: Living conditions of the elderly have a great impact on their quality of life. For both women and men in the 65 and older population, the most prevalent living arrangement is with a spouse, followed by living alone. Women report living alone at more than two times the rate of men.[24] Families, not social service agencies, nursing homes or government programs, are the mainstay of long-term care for older people in the United States. In many cases, both the caregivers and care recipients are aging adults.[25] In Louisiana, it is estimated that in 2003, 5.6 percent of the 65 and older population lived in a total nursing facility, contrasted with the estimate that 5.9 percent of the same population are raising their grandchildren.[26,27]

Being able to do for oneself is an important indicator of well-being, regardless if a person is living alone or living with someone. The number of people age 65 and older who report needing help with personal care has remained steady at just over 6 percent from 1997 to 2003.[28] In the U.S., more than 22.4 million families are serving in a caregiver role for people over the age of 50.[29] Family members and friends provide a supporting and caring atmosphere, transportation to medical services, and social interaction. Difficulties arise when there is not enough time and money to care for a loved one, when caregiver duties interfere with the caregiver's work, and when the caregiver begins to experience stress. Families and even communities must weigh the options of home health care, adult day-care centers, and nursing homes.

Prevention and Services: Access to health care, eating well, staying active, and feeling useful are all important to the elderly. Parish Councils on Aging (COA) programs directly address those issues associated with quality aging, offering a variety of services from volunteer opportunities to meals on wheels. COA centers also provide educational, social, and recreational activities and are a major provider of transportation services. Immunization programs at parish health units and community-based programs provide an easily accessible source of flu and pneumonia shots. Community centers, local health clubs, hospitals and YMCAs offer physical recreation and exercise such as mall-walking and formal exercise classes.

For more information visit the Governor's Office of Elderly Affairs at www.louisiana.gov or Eldercare Locator at 1-800-677-1116 www.eldercare.gov.

Issues Faced by People Living with a Disability

According to The National Organization on Disabilities (NOD) 2004 Harris Survey, significant differences between people with and without disabilities exist in employment, education, community participation, transportation, political participation, health care, religious participation, and use of technology. NOD identifies these differences as "gaps". These gaps span all aspects of a person's life and include such quality-of-life issues as recreation, independence and community participation.[30] Reducing these quality-of-life gaps are the challenges facing community leaders and citizens.

When compared to people without disabilities, people with disabilities:

- spend significantly less time outside the home,
- socialize less,
- feel more isolated,
- participate in fewer community activities, and
- are less likely to be employed.[32]

DID YOU KNOW?

In Louisiana, 48% of survey respondents indicated that they did not have access to needed assistive technology and 70% cited cost as the main reason.[31]

Health Issues Facing People with a Disability

According to Healthy People 2010, (HP2010), health disparities between people with disabilities and without disabilities exist, but are not as documented as are other identified disparities.[33] In response, HP2010 has 13 new objectives designed to improve the health and well-being of people with disabilities and to define gaps and disparities between people with and without disabilities.

Compared to people without disabilities, people with disabilities have:

- less health insurance coverage and use of the health care system,
- higher rates of chronic conditions,
- lower rates of social events,
- fewer community-organized or employee-sponsored health events,
- higher rates of pressure sores in nursing homes,
- higher rates of emergency room visits, and hospitalizations for a primary disabling condition,
- lower rates of formal patient education,
- lower rates of treatment for mental illness,
- more preventable secondary conditions, e.g. fractures, amputation, and
- more early deaths from primary disabling conditions—asthma, diabetes-related cardiovascular disease, or kidney failure.[34]

The CDC is now targeting women with disabilities as an area of emphasis because it recognizes that this population faces additional health issues. Women with disabilities are less likely to get regular screenings such as tests for cervical cancer and mammography screenings, are more frequently affected by many of the conditions that cause disability, and are more prone to secondary conditions, e.g., osteoporosis, obesity and depression.[35]

Working with a Disability

Workplaces and workspaces built for able-bodied people create obstacles for individuals with disabilities. People with disabilities report not only difficulty in finding appropriate work, but also report facing fear, uncertainty, and rejection from people who do not know how to behave around them because they look, move or act differently. Louisiana participants in the DHH 2004 survey of people with disabilities echo these same experiences and concerns: 42 percent of the respondents expressed a level of dissatisfaction when asked about employment opportunities for people with their disabilities, while only 17 percent expressed a level of satisfaction; and 37 percent indicated that their biggest problem in finding work is not enough acceptance of their disabilities.[37]

At the state and national level, the employment rate for people without disabilities is almost two times the rate for people with disabilities. **In St. John the Baptist Parish, 53 percent of those who identified themselves as having a disability also indicated that they were employed—significantly lower than the 72 percent employment rate for people without a disability.**[38]

DID YOU KNOW – *there are many no cost or low cost accommodations that employers can make to hire people with disabilities?*

- *Rearrange an office to provide more maneuvering room.*
- *Allow a technician to sit for a part of the work day.*
- *Give a job applicant with a learning disability extra time to take a test.*
- *Provide a reserved parking space to an employee with a mobility impairment.*[36]

Earnings and Poverty

There is a link between disability and poverty. In the U.S., 17.6 percent of the populations 5 and older with disabilities (8.7 million) live in poverty, compared to only 10.6 percent of the same population without disabilities.[39] **In St. John the Baptist Parish, 20 percent of people with disabilities live in poverty compared to only 15 percent of the population without disabilities**.[40]

Disability and Poverty

	St. John the Baptist	Louisiana	U.S.
% of All Persons Below Poverty	16.1%	19.0%	12.0%
% With a Disability	20.3%	24.9%	17.6%
% With no Disability	15.2%	17.3%	10.6%

Source: U S Census, Census 2000, QT-P21 Summary File 3-Sample Data

People with disabilities who work earn below the median income when compared to people without disabilities. According to Census 2000, in the U.S., people with any of the six specified disabilities who work report a median income of $28,803, which is nearly $4,000 less than people without a disability—in Louisiana they earn nearly $3,000 less when compared to the median income of $28,856 for Louisianans without a disability.[41]

In Louisiana, disabled workers earned nearly $3,000 less

Services and Resources for People with Disabilities

Communities, businesses, and the public sector must recognize that investing in technologies, employment opportunities, and support services for people with disabilities is necessary to increase independence and improve the quality of life for those citizens. These supports provide assistance with such things as housing, transportation, vocational rehabilitation, and in-home personal care attendants (PCA). Many are funded by the federal government and managed by state agencies; others are directed through community and faith-based organizations.

DID YOU KNOW?

In the U.S. in 2002:

- *12.4% of the total population report being limited in their ability to perform daily age appropriate activities due to a physical, mental or emotional problem.*
- *6.1% report needing assistance with personal care, bathing, dressing, and eating.*
- *10.9% report needing assistance with chores such as cooking, housework and managing money, and shopping.*[42]

Identifying and accessing these resources and services is a critical issue for people with a disability, their families and their caretakers. This issue was echoed in results from the DHH survey. The survey identified six problems or issues common to all people with disabilities: Independent living; Personal Care Attendants; Transportation; Waiting for Services; Autonomy; and Difficulty Accessing Information. In the survey, costs and availability were cited as both the main reason for not receiving needed service and as barriers to their ability to live their life as they would like. In brief, the DHH survey results indicated the following:

- **Services available** as often as needed included: inpatient hospital care, emergency care, medications, and specialist doctors.
- **Services not available** as often as needed included: speech therapy, occupational therapy, physical therapy, and personal care attendants.[43]

National Clearinghouse Site for Information

In October of 2002, the federal government launched a one-stop Web site with access to disability information, www.disabilityinfo.gov. This interactive site has information and resources on employment, education, housing, transportation, health, income support, technology, independent living, and civil rights; it also provides links to federal agencies, state services, and community organizations.

Taking Care, Taking Control: Shreveport Church Establishes a Ramp-building Ministry

For the past three years, members of the North Highlands United Methodist Church in Shreveport have traveled to New Orleans, Alexandria, and Monroe to build wheelchair accessible ramps at the homes of persons with disabilities. On the average, the group constructs six to nine ramps a year: Members pay their own travel expenses and provide free labor. If the homeowner cannot afford to pay for the supplies and materials, North Highlands will pay the construction costs.

Backstrom, B., ”Churches put faith into action with ramp-building ministry”, General Board of Global Ministries, The United Methodist Church. 29 Mar 2004.6 Oct 2004. Key words, Churches put faith into action with ramp-building ministry “Global News, Archive 2004, <gbgm-umc.org>.

State Programs and Resources

The state of Louisiana has two Web sites that list services and links to other agencies/groups providing service to Louisiana citizens with disabilities. These are the Louisiana Developmental Disability Council (LDDC) at www.laddc.org and the Louisiana Assistive Technology Access Network (LATAN) at www.latan.org.

The DHH Office for Citizens with Developmental Disabilities (OCDD): OCDD administers the Developmental Disabilities (DD) Services System for people with developmental disabilities. A "developmental disability" is one that is attributable to an intellectual or physical impairment or combination of intellectual and physical impairments; occurs prior to age 22; is likely to continue indefinitely; results in substantial limitations in three or more areas of major life activities, such as self-care, language, learning, mobility, self-direction, and capacity for independent living; and is not attributed to mental illness. The DD Services System includes public and private residential services and other supports and services for people with developmental disabilities. Supports and services are administered through six Region Offices, four Human Service Authorities or Districts, a number of group/community homes, seven Developmental Centers, nine Community Support Teams, and five Resource Centers with defined specialty areas (i.e., psychiatric and behavioral supports; medical and dental supports; nutritional, physical, and nursing supports; inclusion; and aging). OCDD offers a broad range of supports and services including, but not limited to: individual and family supports, such as personal care assistance, respite, and crisis intervention; cash subsidy; extended family living; and supported living services. For more information, visit www.dhh.louisiana.gov, under Offices, "OCDD".

Children's Special Health Services (CSHS): within DHH/OPH, Children's Special Health Services serves as the principal public agency ensuring that children with special health care needs have access to health care services designed to help them live an independent life. CSHS acts as a direct service provider, a case manager or an assistant in managing finances to assure that quality health care services are provided to children with special health care needs. Programs include the Universal Newborn Hearing Screening and Intervention program, the Louisiana Birth Defects Monitoring Network (LBDMN), and EarlySteps—Louisiana's early intervention system for infants and toddlers (birth to 3 years) who have disabilities and developmental delays. This interagency system provides coordinated supports and resources to the families during the initial years of their child's development. CSHS works in partnership with other federal, state and local programs, public and private agencies, institutions, and providers to meet the changing demands of families and children with special health care needs. Additional information is available on-line at www.oph.dhh.louisiana.gov/childrensspecial.

Educational Services for School Age Children with Disabilities: Educational services and supports for school age children, 3-21 years, are delivered through the Louisiana Department of Education, Special Populations Divisions in their Special Education programs mandated by the Individuals with Disabilities Education Act (IDEA) and Section 504. Knowledge of both of these statutes is helpful for parents and caregivers to ensure that their children with disabilities receive an appropriate and barrier- free education. For more information, visit www.doe.state.la.us, Division of Special Populations.

Social Security Disability Benefits: The Louisiana Department of Social Services (DSS) administers benefits to disabled individuals through the Disability Insurance Benefits program and the Supplemental Security Income-SSI. Both programs are funded through the Social Security Administration (SSA) under the Social Security Act. In Louisiana, an individual who qualifies for SSI also qualifies for Medicaid. Often misunderstood is the fact that a person may work and still receive Social Security cash benefits. In Louisiana for 2003, 127,678 people received Social Security disability benefits.[44] Of the total number receiving benefits, nearly 1 in 3 was for a mental disorder, one in four for a muscular/skeletal disorder, and just over 1 in 10 for a circulatory disorder.[45] For more information, visit www.dss.state.la.us/departments/dss/Disability.html.

DID YOU KNOW?

People with disabilities who work may be eligible for the Medicaid Purchase Plan. Under this program, individuals who qualify will get full medical coverage, including prescription drugs, hospital care, doctor services, medical equipment and supplies, and medical transportation. For information call 1-888-544-7996

Louisiana Department of Health and Hospitals

Long-term Care Waiver Programs: Long-term care for people with disabilities is a major concern to the state of Louisiana and is an agenda item of the Governor's Health Care Reform Panel. The essence of the reform is choice for home care or institutional care based on the needs of the individual. One part of a long-term care program is the accessibility to personal care services such as bathing, grooming, household chores, and grocery shopping. Other long-term care programs include adult day health care, group recreational services, and assistance to transition from institutional living to a community living arrangement. For more information, visit the DHH Web site at www.dhh.louisiana.gov, under Offices, "Medicaid" or the DSS web site at www.dss.state.la.us/departments/lrs/Independent_Living.html

DID YOU KNOW?

People with disabilities are an untapped resource of skills and spending power. Work opportunities determine and are determined by the ability to secure affordable, accessible housing, accessible transportation, health care, assistive technology, education, opportunities to socialize, and participate in community and political life.

– N.O.D.

Vocational Rehabilitation: The Louisiana Department of Social Services manages vocational rehabilitation services. Services for the hearing and seeing impaired and services to assist with independent living are all offered through the Louisiana Rehabilitation Services program. Vocational Rehabilitation is a comprehensive career development program offering services ranging from skill development through job placement and career development.[46] Programs serving the hearing and seeing impaired offer a wide range of services designed to help a person with disabilities to maintain his or her independence. Included in these services are access to assistive living devices, an information clearinghouse, and referral services. For more information, visit www.dss.state.la.us/departments/lrs/Vocational_Rehabilitation.html.

Advocacy/Ombudsman: Louisiana has several state offices that provide information and advocacy support to people with disabilities. The Governor's Office of Disability Affairs acts as an advocate and an information repository for people with developmental disabilities. Under DHH, the Developmental Disabilities Council acts as an advocate for people with developmental disabilities while the Office for Citizens with Developmental Disabilities actually runs developmental centers and community services regional offices. Along with state and federal programs, community-based organizations such as Centers for Independent

Living (CIL), The Arc of Louisiana, and LA Citizens for Action Now (LaCAN) are dedicated to keeping people with disabilities independent and to improve their quality-of-life. There are now over 500 centers for independent Living in the United States, with three of these being in Louisiana. **The Louisiana toll free number for information on support and service available to people with disabilities is 1-800-922-DIAL.**

Strategies for Action

National Strategies

The federal government has identified multi-faceted national strategies to address the problems affecting people with disabilities, summarized as follows:

- Improve nutrition and physical activity levels,
- Eliminate physical and attitudinal barriers that hinder full integration into communities,
- Make available long-term care alternatives,
- Provide transportation for the disabled, and
- Develop health screening equipment for people with disabilities.[47]

The National Organization on Disability (NOD) echoes those strategies by suggesting that communities remove barriers of "attitude, architecture and communication."[48] The NOD invites mayors and other community leaders to learn about the disabled people of their community, encourages congregations of all faiths to welcome people with disabilities, informs and educates the disabled on voting rights for citizens with disabilities and challenges emergency managers to address disability concerns. These strategies send a clear message to community leaders: improving the quality of life for people with disabilities requires a multidimensional approach beyond counting parking spaces and buildings with elevators.

Community Strategies

The data presented in this chapter describes the scope and magnitude of disability; however to approach the issues of access and inclusion communities will need to gather information on local resources and services. Community leaders should inventory existing services for people with disabilities, creating an indicator of your community's inclusiveness. Begin by talking to people with disabilities, then include them and their families in community planning. Their experiences will help identify existing service gaps and inclusion barriers. Examples of simple and easy-to-gather indicators are the number and availability of books on tape at the local library or the availability of an interpreter for the hearing impaired at local meetings such as the school board or parish council. Often overlooked indicators are recreational opportunities for people with disabilities. Does your community have wheelchair basketball leagues, or handicapped accessible swimming pools, or lighted and paved walking trails? Another useful indicator is the transportation system. How do people with disabilities get to the doctor or to the store? What public/private disability accessible systems operate in your community?

Examining local business' capacities for hiring the disabled and accessing your communities' volunteer opportunities are also valuable indicators. People with disabilities who volunteer can find opportunities for social inclusion and belonging while fostering friendships and networking possibilities. Another great benefit of volunteerism is the opportunity for

volunteers to develop marketable skills, which in turn can create job opportunities. Communities should identify existing volunteer opportunities and then develop an action plan to link organizations and businesses to this potential volunteer corps. Increasing the "usefulness" of its citizens with disabilities is inherent in creating healthy communities.

The Community Can…

Provide a voice for persons with disabilities [49]

- Develop partnerships between government, people with disabilities, and their advocates.[50]
- Create a commission, board, or position within the local government whose job is to ensure that the needs and interests of persons with disabilities are considered.[51]
- Provide communication aids such as interpreters and assisted hearing devices, at community government meetings.[52]
- Include persons with disabilities in emergency preparedness planning.[53]

Toolkits & Guides:

The Community Tool Box Increasing Access for People with Physical Disabilities, ctb.ku.edu/tools/en/sub_section_main_1223.htm.

Emergency Preparedness initiative, Guide on the Special Needs of People with Disabilities, Community Involvement, Emergency Preparedness, www.nod.org.

Increase options for community–based, consumer choice long-term care[54]

- Support the creation of local family councils and advocacy groups made up of families of persons with disabilities.[55]
- Support education and training for personal care workers to ensure a trained, available work force.[56]
- Facilitate respite programs to provide support for unpaid and family caregivers.[57]

Toolkits & Guides:

Disability Policies and Programs: Lessons Learned, Independent Living and Community Support Services, www11.hrsdc.gc.ca/en/cs/sp/hrsdc/edd/brief/9999-000556/dpp.shtml.

Long-Term Care, www.communitylivingta.info/files/73/3628/Long_Term_Care.pdf.

U.S. Centers for Medicare & Medicaid Services, Promising Practices in Community Services, http://www.cms.hhs.gov/promisingpractices

Increase access to transportation for the elderly and persons with disabilities[58, 59]

- Coordinate transportation services between program–related human service agencies and general public transportation systems.[60]
- Provide disability awareness and sensitivity training for transit operators.[61]
- Create a volunteer driver program utilizing volunteers from faith-based groups, service organizations and the public.[62]
- Encourage and coordinate van pooling, car pooling, and "share-a-ride" initiatives.[63]

Toolkits & Guides:

National Consortium on the Coordination of Human Services Transportation, www.ctaa.org/ntrc/is_coordination.asp.

Easter Seals Project ACTION's Mobility Planning Services, Assessable Community Transportation in our Nation", projectaction.easterseals.com.

United We Ride, Useful Practices, ftawebprod.fta.dot.gov/UsefulPractices.

Senior Transportation: Toolkit and Best Practices, www.ctaa.org/ntrc/senior/senior_toolkit.pdf.

Expand affordable housing opportunities in local communities[64]

- Establish or expand partnerships between the housing system (affordable housing providers and funders) and the disability community
- Educate organizations and individuals about the utilization of programs to support and/or subsidize housing and homeownership, e.g., HUD's Consolidated Plan process and the Section 8 Voucher Program.

Toolkits & Guides:

Going it Alone: The Struggle to Expand Housing Opportunities for People with Disabilities, www.c-c-d.org/going_alone.htm.

Homeownership for People with Disabilities, www.c-c-d.org/od-dec98.htm.

Section 8 Made Simple: Using the Housing Choice Voucher Program to Assist People with Disabilities, www.tacinc.org/cms/admin/cms/_uploads/docs/Sect8.2ndEd.pdf.

Increase employment opportunities for persons with disabilities[65]

- Foster partnerships between employers and community-based, disability focused organizations.[66]
- Offer volunteer opportunities, community service and service learning programs as ways for persons with disabilities to gain marketable job skills.[67]
- Support paid internships for high school students with disabilities to provide valuable work experience and opportunities for job-skill development.[68]

Toolkits & Guides:

Disability Policies and Programs: Lessons Learned- Employment, www11.hrsdc.gc.ca/en/cs/sp/hrsdc/edd/brief/9999-000556/dpp.shtml.

Breaking the Sound Barriers – Employing People Who are Deaf, Deafened and Hard of Hearing, www.chs.ca/info/es/index.html.

Increase social and recreational inclusion opportunities for persons with disabilities [69]

- Develop a community resource directory of local services to the elderly and disabled.[70]
- Provide transportation to community events, and recreational activities.[71]
- Remove barriers to recreational opportunities; ensure recreation and fitness facilities are accessible

Toolkits & Guides:

North Carolina Office on Disability and Health (2001), "Removing Barriers to Health Clubs and Fitness Facilities", Chapel Hill, NC: Frank Porter Graham Child Development Center, www.fpg.unc.edu/~ncodh/FitnessGuide.pdf.

Target interventions to the elderly to minimize the impacts of aging[72]

- Partner with private aging service provider organizations to deliver disease prevention programs.[73]
- Offer physical activity and nutrition programs for the elderly to promote healthy aging.[74]
- Offer fall prevention programs to the elderly.[75]

Toolkits & Guides:

CDC and Merck Institute of Aging and Health, "The State of Aging and Health in America 2004, www.cdc.gov/aging/pdf/State_of_Aging_and_Health_in_America_2004.pdf.

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