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Health Disparities Among Adults with Developmental Disabilities, Adults with Other Disabilities, and Adults Not Reporting Disability in North Carolina

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SYNOPSIS

Objectives. The purposes of this study were (1) to identify disparities between adults with developmental disabilities and non-disabled adults in health and medical care, and (2) to compare this pattern of disparities to the pattern of disparities between adults with other disabilities and adults without disabilities.

Methods. The authors compared data on health status, health risk behaviors, chronic health conditions, and utilization of medical care across three groups of adults: No Disability, Disability, and Developmental Disability. Data sources were the 2001 North Carolina Behavioral Risk Factor Surveillance System and the North Carolina National Core Indicators survey.

Results. Adults with developmental disabilities were more likely to lead sedentary lifestyles and seven times as likely to report inadequate emotional support, compared with adults without disabilities. Adults with disabilities and developmental disabilities were significantly more likely to report being in fair or poor health than adults without disabilities. Similar rates of tobacco use and overweight/obesity were reported. Adults with developmental disabilities had a similar or greater risk of having four of five chronic health conditions compared with non-disabled adults. Significant medical care utilization disparities were found for breast and cervical cancer screening as well as for oral health care. Adults with developmental disabilities presented a unique risk for inadequate emotional support and low utilization of breast and cervical cancer screenings.

Conclusions. Significant disparities in health and medical care utilization were found for adults with developmental disabilities relative to non-disabled adults. The National Core Indicators protocol offers a sound methodology to gather much-needed surveillance information on the health status, health risk behaviors, and medical care utilization of adults with developmental disabilities. Health promotion efforts must be specifically designed for this population.

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Public health and developmental disability researchers have largely overlooked the health of people with mental retardation.¹ A recent groundswell of research and policy efforts has begun to focus attention on disparities between this population and the non-disabled population in health and medical care. In his role as Surgeon General, David Satcher, MD, PhD, released a report titled *Closing The Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation*.² Dr. Satcher lamented that the health of people with mental retardation was not specifically addressed in Healthy People 2010 because appropriate surveillance data were missing for this population. He noted that existing survey-based public health surveillance in the United States is inadequate for identifying people with mental retardation and other developmental disabilities. Dr. Satcher called for a national surveillance system that targets the health status and needs of people with developmental disabilities. In this article, we report on data collected by a statewide surveillance system that could be replicated across the nation.

It is now recognized that a disability can often be complicated by additional medical, psychological, or environmental factors.^{3,4} These secondary conditions range from medical complications such as pressure sores and contractures, to psychosocial adjustment problems, to issues such as limited access to care.⁵

In recognition of the need to improve the quality of life of individuals with mental retardation, Special Olympics, Inc., commissioned a report to examine the health needs of children and adults with mental retardation.⁶ This report highlighted the lack of empirical information about the health status of people with mental retardation. The existing research suggests that, with few exceptions, the prevalences of chronic health conditions (including cardiovascular disease, cancer, lung conditions, and diabetes) in individuals with mental retardation are similar to those in the general population.^{3,7-9} Understanding the risk factors for secondary conditions and strategies for their prevention is important to people with disabilities, rehabilitation service providers, and public health agencies. A study of secondary conditions among adults with developmental disabilities in Montana reported limitations due to communication problems, poor physical fitness, low frustration tolerance, and weight problems.⁹ The authors note that the most serious limitations were associated with significant behavioral or lifestyle issues. These data suggest that several secondary conditions might be targeted for interventions that could improve the health and quality of life of individuals with developmental disabilities while reducing medical care costs.

Research indicates that most individuals with developmental disabilities do not receive the services that their health conditions require.¹⁰⁻¹³ In fact, research on access to and quality of physical, mental, and dental health care demonstrates that individuals with mental retardation face more barriers to health care than the general population.¹⁰⁻¹³ Research has also demonstrated that many primary care providers are unprepared or otherwise reluctant to provide routine or emergency medical and dental care to people with developmental disabilities.^{8,12,14} Many providers refuse to serve people with Medicaid or limit the number of people served under the Medicaid program, a source of coverage for many people with developmental disabilities. Research

has shown that individuals with mental retardation have four to six times the preventable mortality of individuals in the general population,^{15,16} suggesting that appropriate medical care may alter the health trajectories of individuals with mental retardation.

The purpose of this study was to identify disparities in health and medical care between adults with developmental disabilities and non-disabled adults. We were also interested in discovering whether this pattern of health disparities would differ from the pattern found for adults with other, largely physical, disabilities vs. adults without disabilities. We compared data on health status, health risk behaviors, chronic health conditions, and access to medical care across three groups: No Disability, Disability, and Developmental Disability.

METHODS

Data on the health of adults with developmental disabilities living in North Carolina (NC) were compared with data from the 2001 NC Behavioral Risk Factor Surveillance System (BRFSS) survey. BRFSS data are presented separately for respondents who self-selected into disabled and non-disabled groups.

NC BEHAVIOR RISK FACTOR SURVEILLANCE SYSTEM

BRFSS data for 2001 were provided by the NC State Center for Health Statistics. The BRFSS is a random telephone survey of adults designed to collect information about health status, health behaviors, and use of health services related to the leading causes of illness and death.

Since 1998, the NC Office on Disability and Health (NCODH) has included a disability module in the NC BRFSS.¹⁷ Disability status is determined by responses to the following four questions: (1) "Are you limited in any way in any activities because of physical, mental, or emotional problems?" (2) "Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone?" (3) "A disability can be physical, mental, emotional, or communication related. Do you consider yourself to have a disability?" (4) "Because of any impairment or health problem, do you have any trouble learning, remembering, or concentrating?"

For the present study, any respondent who said "yes" to one or more of these questions on the 2001 NC BRFSS was assigned to the Disability group ($n=1,598$). Those who said "no" to all four questions were assigned to the No Disability group ($n=4,358$). BRFSS data reported here are weighted estimates.

BRFSS data are routinely weighted to adjust the sample response by sex (male; female), race (white, non-Hispanic; non-white or Hispanic), and age (18-24; 25-34; 35-44; 45-54; ≥ 65) to match the statewide sex-race-age distribution. This adjusts the sample for non-response or low response among certain demographic groups, such as young white males. The weighting procedure makes the BRFSS data more representative of the total population of adults in the state.

Unfortunately, the BRFSS methodology probably excludes many adults with developmental disabilities because these individuals may not have the opportunity or the cognitive

ability to respond to telephone surveys. Moreover, individuals with developmental disabilities who respond to health surveys over the telephone may not identify themselves as having developmental disabilities.¹⁸

NC National Core Indicators (NCNCI) Project

The National Association of State Directors of Developmental Disabilities Services launched the National Core Indicators (NCI) Project, administered by the Human Services Research Institute, in 1997.¹⁹ The project's aim was to develop nationally recognized performance and outcome indicators that would enable a state's developmental disability service authority to benchmark the performance of its service system against performance levels achieved elsewhere.

In 2000, NC added a Health Indicators module to the NCI protocol to gather surveillance data on the health risk behaviors, health conditions, and medical care utilization of adults with developmental disabilities in the state. Items from the BRFSS were adapted for the Health Indicators. Special consideration was given to unique response biases and other methodological challenges particular to surveying a population with developmental disabilities.²⁰ The Health Indicators items were field-tested in a group of adults with developmental disabilities to verify that they were comprehensible.

Lunskey et al. studied the issue of reporting bias in individuals with developmental disabilities and found imperfect agreement between individuals and proxy respondents (direct support staff) on reports of health-related behaviors and health concerns.²¹ The Lunskey et al. study highlighted the importance of obtaining self-report in addition to caregiver report when possible. The Health Indicators module uses three sources of information. Case managers complete certain items for which information can be found in agency records or information systems, including demographic information about the participant as well as information

about health conditions and medical care services provided. Data on health risk behaviors, health status, and access to medical care are collected in structured face-to-face interviews with study participants; if the individual is unable to respond, a proxy response from a "person that knows him/her well" is accepted. In the development of the Health Indicators interview protocol, every attempt was made to design items that asked for concrete information about recent events or behaviors using simple vocabulary. For the most part, questions are open-ended, and interviewers are instructed to use synonyms and rephrase items for clarity.

The Developmental Disabilities group was a random, unduplicated sample of 946 adults with developmental disabilities living in the community drawn from the North Carolina Developmental Disability Service registry across two years of sampling for the NCNCI (2000–2001, 2001–2002). This sample represents approximately 7% of adults with developmental disabilities receiving services in North Carolina.²² Seventy-six adults living in state-operated mental retardation centers were excluded from the analyses reported here to correspond to BRFSS methodology. NCNCI data are unweighted estimates.

RESULTS

Data are presented for the No Disability, Disability, and Developmental Disability groups on all measures. Data from the NCBRFSS (the No Disability and Disability groups) are weighted estimates; data from NCNCI (the Developmental Disability group) are unweighted.

Demographic information is presented in Table 1. As expected, the Disability group was somewhat older than the other two groups. The Developmental Disability group predominantly (91.3%) consisted of individuals with mental retardation, according to case files. The Developmental Disability sample included slightly more men than women, which

Table 1. Demographic characteristics of study samples

Characteristic	No Disability group (n=4,358)	Disability group (n=1,598)	Developmental Disability group (n=946)
	Percent (95% CI)	Percent (95% CI)	Percent (95% CI)
Male gender	48.5 (46.2, 50.7)	44.1 (40.2, 48.1)	56.1 (52.9, 59.3)
Age			
18–34 years	36.0 (33.7, 38.3)	17.7 (14.6, 21.4)	47.5 (44.3, 50.7)
35–54 years	40.4 (38.2, 42.7)	34.0 (30.4, 37.9)	43.1 (39.9, 46.3)
≥55 years	23.6 (21.8, 25.4)	48.2 (44.4, 52.1)	9.4 (7.5, 11.3)
Education			
Less than high school graduate	11.9 (10.3, 13.7)	26.8 (23.6, 30.4)	—
High school graduate or GED	32.1 (30.0, 34.3)	34.6 (30.9, 38.6)	—
Some post-high school	24.9 (23.1, 26.8)	22.2 (19.4, 25.4)	—
College graduate	31.1 (29.1, 33.2)	16.3 (13.7, 19.2)	—
Severity of mental retardation			
Mild	—	—	39.4 (36.3, 42.5)
Moderate	—	—	26.6 (23.8, 29.4)
Severe	—	—	14.7 (12.4, 17.0)
Profound	—	—	10.6 (8.6, 12.6)

NOTES: Point estimates for the No Disability and Disability groups are weighted. Point estimates for the Developmental Disability group are unweighted.

is consistent with the reported male-to-female ratio for people with mental retardation (1.5 male:1 female).²³ People with mild mental retardation made up approximately 40% of the Developmental Disability sample.

General health status

Table 2 presents the general health status for the No Disability, Disability, and Developmental Disability samples of adults in NC. Not surprisingly, adults in both the Disability and Developmental Disability groups were significantly more likely to be in fair or poor health than adults without disabilities. On the Core Indicators survey, the health status question was included only in 2001–2002 ($n=514$).

Health risk behaviors

Physical activity. As shown in Table 3, individuals in the Disability and Developmental Disability groups were significantly more likely to have had no exercise in the previous month than those in the No Disability group.

Tobacco use. Almost 25% of the No Disability sample reported that they smoked cigarettes. Although adults with developmental disabilities had the lowest smoking rate of the three groups, their rate was not significantly lower than that for adults with No Disability.

Obesity. Body mass index data were available only for the 2001–2002 Core Indicators survey ($n=514$), and some responses were missing for this item, leaving $n=477$ for the Developmental Disability group. There were no significant differences between the groups in the percentages of respondents classified as overweight/obese.

Inadequate emotional support

As shown in Table 3, adults in the Developmental Disability group were also more likely than those in the No Disability group to lack adequate emotional support; an alarming 24% of adults with developmental disabilities reportedly either had no one to talk with about personal things or often felt lonely.

Only 61.7% of adults with developmental disabilities reportedly could see their family members whenever they wanted (not shown). Transportation or staffing limitations were cited as barriers to spending time with friends by or for 18.1% of these adults.

Chronic health conditions

We present data on the following chronic health conditions: high blood pressure, cardiovascular disease, arthritis, diabetes, and chronic pain.

As shown in Table 4, individuals in the Disability group were significantly more likely than those in the No Disability group to suffer from each of the chronic health conditions. Especially striking is the higher risk for chronic pain in the Disability group relative to the No Disability group (relative risk [RR] = 16.2). People with developmental disabilities were more likely to have a diagnosis of diabetes than people without disabilities. Interestingly, adults with developmental disabilities were less likely to be diagnosed with arthritis.

Medical care utilization

Cervical and breast cancer screening. Women with developmental disabilities were significantly less likely to have had routine breast and cervical cancer screenings than women without disabilities (Table 5). It is striking that 11.5% of women with developmental disabilities reportedly had never visited a gynecologist. Women with developmental disabilities were significantly less likely than women without disabilities to have had a mammogram. Although women in the U.S. are advised to have mammograms every one or two years beginning at age 40,²⁴ 26.8% of women with developmental disabilities age 40 or older in this study reportedly had never had a mammogram.

Oral health services. As shown in Table 5, significant disparities in oral health care were noted for the Disability group relative to the No Disability group. For the Core Indicators survey, data were available only for 2001–2002 ($n=514$), and some responses were missing for this item, leaving $n=477$ for the Developmental Disability group. Individuals with developmental disabilities were more likely than those in the No Disability group not to have had their teeth cleaned in the past five years or never to have had their teeth cleaned. These disparities are especially striking given that the non-disabled population of adults in North Carolina did not fare well on these measures.

DISCUSSION

The purpose of this project was to identify disparities between adults with developmental disabilities and the non-disabled population in health status and medical care. We

Table 2. General health status

	No Disability group ($n=4,358$)	Disability group ($n=1,598$)		Developmental Disability group ($n=514$)	
	Percent (95% CI)	Percent (95% CI)	χ^2	Percent (95% CI)	χ^2
Excellent	26.6 (24.7, 28.6)	6.7 (5.2, 8.7)	14.9 ^b	20.3 (16.6, 24.0)	1.5
Good	67.4 (65.4, 69.5)	45.5 (41.7, 49.4)	7.1 ^a	60.8 (56.4, 65.2)	0.6
Fair/poor	5.9 (5.0, 7.0)	47.8 (43.9, 51.6)	297.6 ^b	18.4 (14.9, 21.9)	26.5 ^b

NOTES: Point estimates for the No Disability and Disability groups are weighted. Point estimates for the Developmental Disability group are unweighted. Pearson χ^2 results are for comparisons with the No Disability group.

^a $p<0.01$.

^b $p<0.001$.

Table 3. Health risk behaviors

	No Disability group (n = 4,358)	Disability group (n = 1,598)		Developmental Disability group (n = 946)		χ^2
	Percent (95% CI)	Percent (95% CI)	RR (95% CI)	Percent (95% CI)	RR (95% CI)	
No exercise past month	22.5 (20.6, 24.5)	36.8 (33.5, 40.5)	1.6 (1.4, 1.9)	33.7 (30.4, 37.0)	1.5 (1.3, 1.7)	5.6 ^a
Smoke cigarettes	24.8 (22.8, 26.9)	28.5 (25.0, 32.2)	1.2 (1.0, 1.3)	17.8 (14.9, 20.7)	0.7 (0.6, 0.9)	2.0
Overweight/obese	56.8 (54.4, 59.1)	66.2 (62.5, 69.7)	1.2 (1.1, 1.3)	59.6 ^d (54.2, 65.0)	1.1 (1.0, 1.2)	0.2
Inadequate emotional support	3.5 (2.6, 4.7)	6.8 (5.0, 9.2)	1.9 (1.2, 2.9)	24.0 ^e (21.0, 27.0)	6.9 (4.9, 9.6)	120.1 ^c

NOTES: Point estimates for the No Disability and Disability groups are weighted. Point estimates for the Developmental Disability group are unweighted. Pearson χ^2 results and relative risks are for comparisons with the No Disability group.

^ap<0.05

^bp<0.01

^cp<0.001

^dn=477

^eReported no one to talk with about personal things or often feels lonely.

CI = confidence interval

RR = relative risk

Table 4. Chronic health conditions

	No Disability group (n=4,358)	Disability group (n=1,598)		Developmental Disability group (n=477)		χ^2
	Percent (95% CI)	Percent (95% CI)	RR (95% CI)	Percent (95% CI)	RR (95% CI)	
High blood pressure	20.7 (19.1, 22.5)	47.5 (43.6, 51.4)	2.3 (2.0, 2.6)	16.0 (12.7, 19.3)	0.8 (0.6, 1.0)	1.1
Cardiovascular disease	3.5 (2.5, 5.0)	22.9 (18.6, 27.9)	6.5 (4.3, 9.7)	7.1 (4.8, 9.4)	2.0 (1.3, 3.1)	3.7
Arthritis	15.3 (13.8, 17.0)	47.1 (43.3, 51.0)	3.1 (2.7, 3.5)	4.9 (2.9, 6.9)	0.3 (0.2, 0.5)	7.1 ^b
Diabetes	3.9 (3.2, 4.8)	15.2 (12.8, 18.0)	3.9 (3.0, 5.1)	7.9 (5.5, 10.3)	2.0 (1.4, 2.9)	4.1 ^a
Chronic pain	1.8 (1.1, 2.8) ^d	28.4 (23.6, 33.8) ^d	16.2 (9.9, 26.3)	3.0 (1.4, 4.6)	1.7 (0.8, 3.3)	0.8

NOTES: Point estimates for the No Disability and Disability groups are weighted. Point estimates for the Developmental Disability group are unweighted. Pearson χ^2 results and relative risks are for comparisons with the No Disability group.

^ap<0.05

^bp<0.01

^cp<0.001

^dPain 15–30 days in past month

CI = confidence interval

RR = relative risk

Table 5. Medical care utilization

	No Disability group		Disability group			Developmental Disability group		
	Percent (95% CI)		Percent (95% CI)	RR (95% CI)	χ ²	Percent (95% CI)	RR (95% CI)	χ ²
Never had Pap test (female respondents) ^a	<u>n=797</u>		<u>n=212</u>			<u>n=415</u>		
	2.2 (1.3, 3.7)		4.7 (2.6, 8.2)	2.1 (1.0, 4.6)	2.8	11.5 (8.4, 14.6)	5.2 (2.9, 9.5)	39.3 ^d
Never had mammogram (female respondents ≥40 years of age)	<u>n=623</u>		<u>n=282</u>			<u>n=160</u>		
	13.0 (10.3, 16.3)		14.5 (10.5, 19.7)	1.1 (0.8, 1.7)	0.2	26.8 (19.4, 34.2)	2.1 (1.4, 3.0)	14.6 ^d
Never had dentist visit or no visit for ≥5 years	<u>n=4,358</u>		<u>n=1,598</u>			<u>n=946</u>		
	9.4 (8.2, 10.8)		19.9 (16.8, 23.5)	2.1 (1.7, 2.6)	11.7 ^d	5.5 (4.0, 7.0)	0.6 (0.4, 0.8)	1.6
Never had teeth cleaning or no cleaning for ≥5 years	8.0 (6.8, 9.4)		17.2 (13.9, 21.2)	2.2 (1.6, 2.8)	10.6 ^c	14.4 ^e (11.1, 17.7)	1.8 (1.4, 2.4)	5.1 ^b

NOTES: Point estimates for the No Disability and Disability groups are weighted. Point estimates for the Developmental Disability group are unweighted. Pearson χ² results and relative risks are for comparisons with the No Disability group.

^aLimited to women who had not had a hysterectomy. For the No Disability and Disability group, the respondent was asked if she had ever had a Pap test. For the Developmental Disability group, the survey item was "Never had an ob/gyn exam."

^bp<0.05

^cp<0.01

^dp<0.001

CI = confidence interval

RR = relative risk

were also interested in discovering whether the patterns in adults with developmental disabilities would differ from the patterns found in adults with other, largely physical, disabilities.

Disability group

Those in the Disability group were significantly more likely than adults without disabilities to describe their general health status as fair or poor. In terms of health risk behaviors, the Disability group was significantly more likely to report a sedentary lifestyle, with more than one-third of the sample reporting no exercise of any kind in the past month. Increasing physical activity has been targeted as an objective of Healthy Carolinians 2010, the statewide implementation of Healthy People 2010. Adults in the Disability group were significantly more likely to experience several chronic diseases than those in the No Disability group. Significant differences were found for all five health conditions measured: high blood pressure, cardiovascular disease, arthritis, diabetes, and chronic pain. Finally, significant disparities in oral health care were found; adults with disabilities were twice as likely not to have visited the dentist in the past five years and not to have had their teeth cleaned ever or in the past five years.

Developmental Disability group

When compared to the No Disability group, adults with developmental disabilities were significantly more likely to have fair or poor general health status. The Developmental Disability group reported the same or greater health risks than the No Disability group. Specifically, adults with developmental disabilities were significantly more likely to have a sedentary lifestyle, with approximately one-third of the sample reportedly having had no exercise of any kind in the past month.

The data show that adults with developmental disabilities had an alarming rate of inadequate emotional support. A full 24.0% of these adults reportedly had no one to talk to about personal things or often felt lonely, a significantly higher rate than in the No Disability group ($RR=6.9$). In the general population, emotional support has been found to protect against health problems such as heart disease and depression.^{25,26} Men and women with developmental disabilities have been shown in earlier studies to have significantly less emotional support than those in the general population.^{27,28} The absence of emotional support has been found to correlate with poorer quality of life^{29,30} and mental health problems for people with developmental disabilities.^{31,32}

Transportation and staffing limitations present unique barriers to interpersonal relationships as well as to recreation and physical activities for adults with developmental disabilities. Transportation was identified in the Developmental Disabilities Act as one of eight areas of emphasis for Administration on Developmental Disabilities programs.³³

People with disabilities are at elevated risk for a variety of preventable medical problems that can limit health, functional capacity, participation in life activities, and independence.³ For the most part, respondents in the Developmental Disabilities group had the same or higher rates of chronic health conditions compared with those without disabilities.

Adults with developmental disabilities were significantly more likely to have diabetes and less likely to have a diagnosis of arthritis. The possibility that arthritis and chronic pain are underdiagnosed in people with limited communication skills should be considered.

Access to medical care services was raised as a concern for individuals with developmental disabilities in the 2002 Surgeon General's report.² We compared service utilization for women's health and dental care, two areas highlighted by the Surgeon General.² Significant disparities in breast and cervical cancer screening as well as oral health care were found for adults with developmental disabilities relative to the No Disability group.

Adults with mental retardation face many barriers to oral health care.³⁴ The data reported here show significant disparities between the Disability and No Disability groups in receipt of oral health care, and a poorer history of teeth cleaning among developmentally disabled adults than among non-disabled adults. Healthy Carolinians 2010 set an objective of increasing to 73.9% the number of adults who visit the dentist yearly. In addition to its impact on oral health, there is increasing concern that routine cleaning and healthy teeth and gums may play a role in preventing cardiovascular disease and stroke.

Disability group compared to Developmental Disability group

Although the Disability and Developmental Disability groups were not directly compared, some observations can be made about the pattern of findings for each group relative to the No Disability group. Many similarities were found. Individuals in both the Disability and Developmental Disability groups were more likely to have fair or poor health status than individuals in the No Disability group. Both groups had higher rates of physical inactivity than the No Disability group. A higher risk of diabetes was found in both groups, as well as a greater likelihood of not having had their teeth cleaned ever or in the past five years.

Striking differences were noted as well. While there was no difference in reports of inadequate emotional support between the Disability and No Disability groups, adults with developmental disabilities were nearly seven times as likely as non-disabled adults to report experiencing inadequate emotional support. Significant differences were found between the No Disability group and the Disability group, but not the Developmental Disability group, on the risk of high blood pressure, cardiovascular disease, and chronic pain. Conditions such as high blood pressure could be the primary condition accounting for a disability, or a secondary condition. A secondary condition constitutes an additional (preventable) burden of disease for individuals whose underlying disability results from a different cause, such as spinal cord injury. Finally, women in the Developmental Disability group differed from non-disabled women in utilization of reproductive medical care (Pap test and mammogram). This unique disparity may be attributable to society's prevailing perception of women with developmental disabilities as childlike and asexual, and therefore not needing breast or cervical cancer screening.

Limitations

There are a number of limitations to these analyses. First, NCNCI includes only adults with developmental disabilities who are receiving services. It is estimated that approximately half of individuals with mild mental retardation do not access services in adulthood;³⁵⁻³⁷ thus, people with mild mental retardation may have been under-represented in this study. Further, BRFSS interviews are conducted by telephone and do not reflect the experience of individuals unable to communicate by telephone or those living in congregate homes or homes without telephones. Previous studies have found that people living in households without telephones are more likely to be of lower socioeconomic status and have more risk factors for chronic disease than those living in households with telephones.³⁸ However, this limitation is relatively minor, with only 3.0% of NC households being without telephone service, according to the NC Rural Economic Development Center.³⁹

Another limitation of the study is that it was necessary to use two data sources (BRFSS and NCNCI) to compare the three populations of interest. However, because the NCNCI sample was randomly selected, these findings are representative of adults living in the community who receive developmental disability services in North Carolina. A final limitation is that BRFSS data and some of the NCNCI data were self-reported; previous studies, however, have suggested that adults with mental retardation²¹ and adults responding to the BRFSS⁴⁰ provide reliable self-reports of health information.

CONCLUSIONS

Health promotion, disease prevention, early detection, and universal access to care are the cornerstones of a balanced community health system. Individuals with developmental disabilities face barriers in each of these areas. The medical and dental care of individuals residing in the community must be obtained from community-based providers, yet many health professionals have little exposure to individuals with developmental disabilities and, as a result, are sometimes uncomfortable treating them. In order to ensure access to quality services, there is a need for specialized training for health professionals. This need was recognized in the Developmental Disability Act, first authorized in 1962.

In this study, disparities were found in medical care utilization for adults with developmental disabilities as well as other disabilities, relative to the non-disabled population. High rates of poverty among individuals with developmental disabilities mean that many rely on publicly financed health insurance and services. People with developmental disabilities find that many providers avoid Medicaid and other public programs, citing low reimbursement rates, administrative burden, and fear of being inundated with patients who may require special time and attention. Dental care for adults is particularly challenging in that, by and large, Medicaid does not cover adults' dental care.¹⁴ Providers who are committed to treating individuals with developmental disabilities report that restrictive Medicaid regulations and reimbursement rates can limit innovative service models. Research is needed on financing structures that better accommodate individuals with developmental disabilities. This research will depend on accurate medical care utilization data.

Surveillance is needed that targets the health status and needs of people with developmental disabilities. This will allow for the tracking of health status, risk behaviors, quality of life, chronic health conditions, and medical care utilization. Such surveillance is challenging given a number of factors including the nature of these disabilities, which may limit accurate self-reporting and ready access to a telephone, and the fact that people may be reluctant to disclose having a developmental disability because of stigma. The NCI protocol offers a sound methodology to gather this much-needed surveillance information. One advantage of the NCI methodology is that information is gathered from three sources.²¹ The NCI protocol gathers information from the individual with a developmental disability, which is critically important for a valid picture of subjective indicators such as pain and emotional support. NCI also gathers information from a proxy reporter who knows the individual well when the individual is unable to respond to the interview items. Finally, accurate data about health conditions and medical care utilization are gathered from the case manager. Another advantage of NCI as a health surveillance protocol is that random samples of adults receiving state developmental disability services are selected, thus assuring their representativeness. This methodology offers a unique window through which to view the health of people with developmental disabilities. A state implementing the NCI protocol may collect additional data on health risk behaviors and specific health conditions to identify risks and conditions that are likely to be prevalent or that are the most severe and costly. Local barriers to medical care could also be identified. Such data would allow policy makers, administrators, advocates, and program designers to develop programs and training that address these problems. An NCI-based health surveillance system could be used on an ongoing basis to monitor the effects of such systemwide interventions across the population.

Goals for health promotion include education regarding the risks associated with various health behaviors as well as promoting a commitment to a healthy lifestyle. Our findings suggest a need for health promotion efforts specifically designed for people with developmental disabilities, focused on physical fitness, weight control, smoking cessation, emotional support, and disease prevention. Empirical research is needed to find educational approaches that are effective for individuals with developmental disabilities, many of whom may not understand traditional strategies such as television or radio public service announcements and printed materials. In many instances, it may be more effective to direct efforts at the developmental disability service delivery system. In addition, health promotion programs available in the community and clinical settings for the general population should be responsive to people with developmental disabilities. Disability service providers and advocates must partner with health educators to ensure that educators receive the necessary information, training, and support to provide accessible services. A greater emphasis must be placed on designing health promotion initiatives that reach people with disabilities, and the NCI protocol and the BRFSS can serve as important public health tools for measuring state and national progress over time.

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