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Putting People First: Services and Supports for People with Developmental Disabilities

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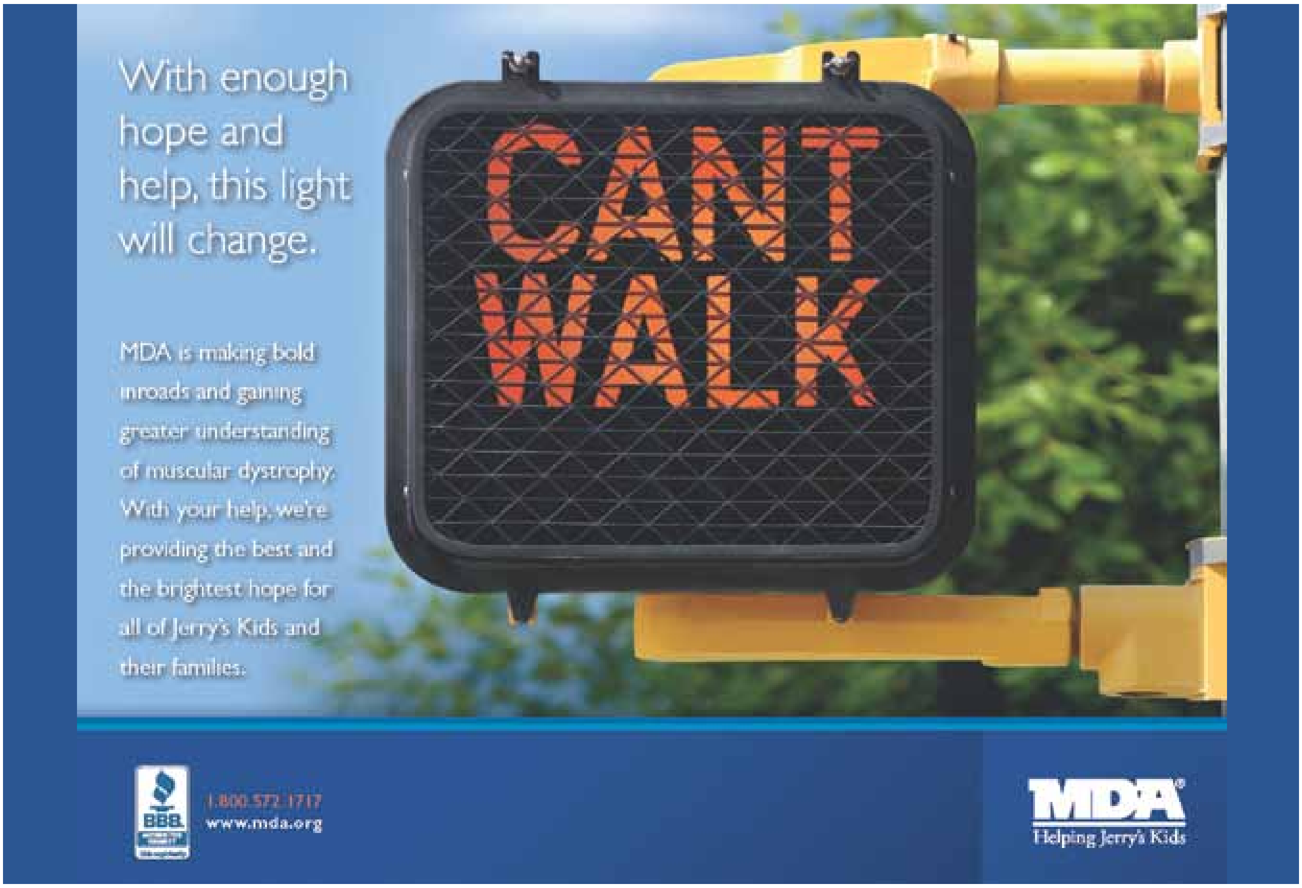

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Tarheel Footprints in Health Care

Recognizing unusual and often unsung contributions of individual citizens who have made health care for North Carolinians more accessible and of higher quality

Adonis Brown
Self Advocate and Independent Living Consultant

Adonis Brown was born without arms. Many would consider this a huge barrier to a "normal" life but this has not stopped him from achieving a full life that has improved the lives of others. As an advocate for his own goals, as a motivational speaker, and as an independent living consultant he has enabled many to accomplish more than they might have thought possible.

"I've learned never to give up and not to take negative advice," Mr. Brown said recently. "If someone says I can't do something, that makes me want to do it even more." Mr. Brown has devoted his life and professional career to helping individuals with disabilities realize their full potential and achieve their personal goals. He is the founder and president of EnVisioned Independent Living, an organization that is dedicated to helping people with intellectual and other developmental disabilities learn adaptive skills for independent living. EnVisioned provides educational and support services such as counseling, mentoring, and advice on workplace issues. They conduct motivational and sensitivity workshops, and provide life skills training to help individuals achieve independent living lifestyles.

Growing up, Mr. Brown was told by occupational therapists that he would always have to rely on someone to help with all the basic daily living activities. "It was not that the therapists did not know what they were doing," Brown says. "It was and is that my needs are beyond today's training. They all felt that dressing and bathing and things like that were going to be things that I would always need assistance with." However, through perseverance and self-determination, Mr. Brown successfully learned how to live life independently. Recently, in a video produced by the North Carolina Council on Developmental Disabilities, Mr. Brown was filmed saying, "The biggest battle is—to me—mindset. People still do not grasp a full understanding that persons with disabilities, no matter what disability, no matter how severe that disability is, they still deserve the right to reach their full potential in life. Whatever their full potential may be—society should try to help them reach it."

When asked about Mr. Brown, Larry Swabe, assistant director for program management at the North Carolina Council on Developmental Disabilities responded, "Adonis Brown serves as a visible and respected leader in the developmental disabilities arena. Adonis can be found at many of the places where his leadership is put into practice, serving on the board of Disability Rights North Carolina, the gubernatorial appointee to the North Carolina Council on Developmental Disabilities, and selected for participation on the North Carolina Summit on Developmental Disabilities—just to name a few."

Mr. Brown is currently working on his bachelor's degree in psychology and is an active member of the North Carolina Council on Developmental Disabilities, the Arc of North Carolina, NC TASH, and the National Council on Independent Living. He also serves on the Durham Mayor's Committee for People with Disabilities and was the 2006 recipient of the North Carolina Advocacy Network's Vision in Action Award.

Contributed by Lindsey E. Haynes, a graduate student in the Department of Health Policy and Management, University of North Carolina at Chapel Hill, Gillings School of Global Public Health with the assistance of Jill Rushing, program manager at the North Carolina Council on Developmental Disabilities.

North Carolina MEDICAL JOURNAL

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PEER-REVIEWED ARTICLES

HEALTH REFORM IN NORTH CAROLINA

POLICY FORUM

Putting People First: Services and Supports for People with Developmental Disabilities

COMMENTARIES

DEPARTMENTS

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Type Practice	***Location***	***Practice Price***	***Real Estate***	***Total Listing Price***
Internal Medicine This practice is a mainstay of the community. Retiring physician is willing to stay for a few days per week to mentor and help with transition. Currently treating internal as well as gastrological patients.	**Durham County, NC**	**$176,000**	**$165,000**	**$341,000**
Internal Medicine New listing for this established Internal Medical practice. Quality exam tables, completely furnished, with large lobby. The medical building has two sides, and the new physician may lease one or both sides. This is a great practice to continue as an IM practice or expand to family or urgent care. Specialized practices would also be successful in this facility. Owner may be willing to finance half of the asking price for a qualified MD.	**Shelby, NC**	**$300,000**	**Leased**	**$300,000**
Women's Practice Primary care with a woman's touch. This is an established and well-known practice in the heart of Wake County. Upscale, with new computer system and exceptional staff. The physician is willing to stay for several months, assuring a smooth transition. Two-story building, fully leased to MDs with excellent cash flow.	**Wake County, NC**	**$725,000**	**$1,750,000**	**$2,475,000**
Pain Management Established 3 years ago, this practice with multiple locations is profitable and poised for continued growth. The main practice building is owned, and the two other satellite locations are leased. Digital X-Rays in each location, with extensive treatment equipment. MD is willing to continue with the practice for several months.	**Indianapolis, IN**	**$785,000**	**$950,000**	**$1,735,000**
Hyperbaric Oxygen Therapy This practice, owned by an investment group, is fully equipped and ready for a new owner. Two treatment chambers; well-appointed. This practice has been open for one and a half years and is ideal for an on-site MD. It can also become an extension of your existing practice. Owner is willing to finance part of the purchase price.	**Raleigh, NC**	**$357,900**	**Leased**	**$357,900**
Urgent Care Upscale practice serving patients in the Triad for about 15 years. Medical equipment includes X-Ray, CBC and several up-fitted exam rooms with Welch Allyn Otoschopes. Consistent patient flow including walk-ins and corporate accounts. MD is retiring for health reasons.	**Greensboro, NC**	**$350,000**	**Leased**	**$350,000**
Internal Medicine This primary care practice is a medical cornerstone of the community, serving metropolitan Greenville and surrounding areas. Impressive 40 patients per day. MD is willing to stay up to one year to assist with ownership transfer.	**Greenville, NC**	**$600,000**	**$160,000**	**$760,000**
Neuropsychological This highly regarded practice offers psychological services that include diagnostics, rehabilitation, behavior medicine and specialized programming to include day treatment for brain-injured adolescents and adults. Referral base includes hospitals, doctors, insurance companies, attorneys and case managers.	**Charlotte, NC**	**$640,000**	**Leased**	**$640,000**
Orthopaedic This hospital-based orthopaedic and sports medicine practice is established with X-Ray, experienced staff and internal electronic billing. Physician is retiring but willing to stay for several months to assist the new owner.	**Tidewater, VA**	**$200,000**	**Leased**	**$200,000 Reduced**
Urgent Care This established urgent care is located about 40 minutes south of Raleigh. Fully equipped with X-Ray, and the staff is seasoned. The owner has another practice out of the area and wishes to sell this location.	**Johnson County, NC**	**$185,000**	**Leased**	**$185,000**

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PEER-REVIEWED ARTICLE

North Carolina All-Terrain Vehicle (ATV) Safety Legislation:

An Assessment of the Short-Term Impact on ATV-Related Morbidity and Mortality

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Stephanie K. Beidler, MD; Sharon Kromhout-Schiro, PhD; Christelle D. Douillet, PhD;
Paul J. Riesenman, MD; Preston B. Rich, MD

Abstract

Objective: *All-terrain vehicle (ATV)-related morbidity and mortality has increased in the US, and states have attempted to combat this trend with ATV-specific safety legislation. The objective of this study was to examine the short-term changes in ATV-related injuries and deaths following the enactment of legislation regulating the operation and sale of ATVs in North Carolina.*

Study Design and Data Collection: *The study is a retrospective analysis comparing ATV collisions during the six month pre and post period of the effective date of legislation. Demographics, medical outcomes, passenger seat position, helmet use, and alcohol use were analyzed.*

Data: *Subjects were identified through the North Carolina Trauma Registry and data from the Office of the Chief Medical Examiner.*

Findings: *A total of 102 (51 in both pre- and post-legislation) subjects required medical treatment or were declared dead secondary to ATV collisions in North Carolina. Children under the age of eight years, who were forbidden from using ATVs under the new legislation, had significantly fewer total medical evaluations and deaths in the post-legislative time period. There was no association between legislative time period and ATV-related passenger, helmet, or alcohol use.*

Conclusions: *In the six months following the enactment of North Carolina's ATV bill, children under the age of eight years were seriously injured or died less often due to ATV-related crashes. No other significant changes in ATV riding patterns were seen between the two time periods, and the morbidity and mortality of all ATV riders did not change.*

Limitations: *The examined data sets do not include data from all North Carolina hospitals.*

Keywords: *all-terrain vehicle (ATV), legislation, pediatric trauma*

The United States Consumer Product Safety Commission (CPSC) reported that 7,188 all-terrain vehicle (ATV)-related deaths occurred nationally between the years 1982-2005; 30% of the deaths were children under the age of 16. North Carolina was the 10th highest state in the number of ATV-related fatalities. In 2005, 136,700 ATV-related injuries were evaluated in emergency rooms across the United States, compared to 10,100 in 1982.[1] The escalating morbidity and mortality associated with ATVs is directly linked to the increasing use of these vehicles.[2]

Risk factors for ATV injury include driver age under 16 years, male gender, operator inexperience, alcohol or drug influence, helmet absence, recreational driving, and three-wheeled ATV use.[3-5] Based on risk factor data, the CPSC entered into a consent decree agreement with ATV manufacturers in 1988. This decree, which expired in 1998, implemented a nationwide ATV driver training program, ceased production and sales of three-wheeled ATVs, imposed stringent driver age requirements, and developed voluntary safety standards.[6] Presently, several manufactures

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have continued many elements of the decree on their own initiative.

Forty-four states have responded to escalating ATV-related morbidity and mortality by instituting safety legislation.[7] Helmets and other safety equipment are now required by almost half of the states.[3,8] Many states also impose limits on vehicle size and restrict ATV use to off public roadways. According to an article published in the *American Journal of Public Health*, ATV-related death rates in states without ATV helmet or machine safety regulations were twice that of states with safety measurements in place.[8] A study comparing injury rates and helmet use between Pennsylvania, which has ATV regulations, and North Carolina (prior to the passage of the ATV bill) showed that those living in Pennsylvania had decreased risk factors for ATV injury.[9] State laws have reduced ATV-related injuries and death; however, the time course of the impact of these laws has not been studied.

The North Carolina legislature passed Senate Bill 189 in August 2005 and North Carolina Governor Michael F. Easley signed this bill into law. This legislation regulates the sale and operation of ATVs and took effect on December 1, 2005. Prior to the passage of this bill, North Carolina did not have any ATV safety requirements. The objective of this study was to assess the effectiveness of this legislation in the first six months after the law went into effect. We hypothesized that in the initial period following the enactment of this bill, the ATV-related collision data would show a reduction in the following areas compared to an equivalent pre-legislation time period:

1. The number of patients less than eight years of age assessed at Level I/II trauma centers and killed secondary to ATV crashes. *Rationale*: The North Carolina law forbids the use of ATVs by persons under the age of eight years.
2. The morbidity and mortality of victims involved in ATV accidents between the ages of 8 and 15 years. *Rationale*: The law restricts the operation of ATVs by persons 8 to 15 years old based on engine capacity. Children must also operate ATVs under the direct supervision of an adult.
3. The number of people involved in ATV accidents not wearing helmets. *Rationale*: According to the new law, all people operating an ATV must wear a safety helmet.
4. The number of ATV-related deaths secondary to head injury. *Rationale:* The increased use of helmets has been shown to reduce mortality due to head injuries.
5. The detection or suspicion of alcohol use in ATV accident victims. *Rationale*: The legislation mandates that no person is to operate an ATV under the influence of alcohol.
6. The number of ATV passengers. *Rationale*: The law states that ATV passengers are not allowed, except on those vehicles specifically designed by the manufacturer, to carry passengers in addition to the operator.

Methods

The Institutional Review Board at the University of North Carolina at Chapel Hill granted approval for the study. Data was obtained from the North Carolina State Trauma Registry (TR) and the Office of the Chief Medical Examiner (OCME). Subjects were then placed into either pre-legislation (December 1, 2004-May 1, 2005) or post-legislation (December 1, 2005-May 1, 2006) categories based on the date of the ATV-related injury evaluation or death.

Patients included in the TR data were assessed at North Carolina Level I and II Trauma Centers and were either admitted to the hospital, died in the emergency department, or transferred to the operating room or another hospital. Subjects involved in ATV collisions occurring outside of North Carolina (but were transferred to North Carolina hospitals for treatment) were excluded.

The TR registry was queried for E-codes (External Causes of Injury) specific to ATV injuries (821.0, 821.1, 821.8, and 821.9) and reviewed for unexpected results. The OCME files were queried for all ATV-related deaths. The OCME patients' cause of death was coded using the *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM).

Data was assessed using chi-squared and Fisher exact (two-tailed) statistics, and clinical significance was set at $p< 0.05$. The data is presented as means $\pm$ standard deviations.

Results

Both the pre- and post-legislation data had 51 subjects involved in ATV collisions resulting in either medical intervention or death. The majority of the ATV-crash subjects were white males in their mid-20s who were using ATVs for recreational or sporting activities.

The data are presented in Table 1. Children under eight years of age had significantly fewer ($p=0.0267$) medical evaluations ($n=5$) and deaths ($n=1$) related to ATV collisions compared to an equal pre-legislative period. No other comparisons reached statistical significance. The TR injury severity scores (ISS) of the pre-legislation group was 13.7 ± 12.9 compared to 8.6 ± 8.8 (mean $\pm$ standard deviation) in the post-legislation group (where ISS ≥ 1). There were a total of 10 deaths in each set per the OCME data.

Discussion

The North Carolina ATV safety bill was created to reduce the morbidity and mortality related to ATV use. An examination of the immediate impact of the bill indicates significant reduction in the collisions requiring medical evaluation and/or deaths of children eight years or younger riding ATVs. This is an encouraging change; however, the law did not further impact overall ATV riding behavior. Several aspects of the North Carolina law may limit its effectiveness: the present penalties may not be stringent enough to encourage behavioral changes in all users;

Table 1.
ATV-Related Collision Subjects in Pre- and Post-Legislative Time Periods

Assessing Hypotheses	Pre-	Post-	Significance
Subjects less than eight years of age requiring medical assessment or dying secondary to ATV-crashes	6	0	p=0.0267
Subjects ages 8-15 years requiring medical assessment or dying secondary to ATV-crashes	14	12	*NS*
All ATV subjects not wearing helmets	11	18	*NS*
All ATV deaths secondary to head injury (ICD-9 codes)*	5	4	*NS*
All ATV subjects with alcohol use measured or suspected	9	10	*NS*
All passengers on ATV*	1	0	*NS*

*OCME data only.
NS = Not significant.

farmers, hunters, and trappers in North Carolina are exempt from the law; children already using an ATV who were born before August 15, 1997 do not have to abide by the engine capacity limitations; and ATV safety training certification was required starting October 2006, which was after the post-legislative period examined in this study, but which only included ATV operators born after 1990.

The importance of effective legislation and risk prevention cannot be emphasized enough. People with a history of ATV/motorcycle injury are less likely to use a helmet or protective equipment and are more likely to continue to have patterns of persistent high risk behavior.[10] For example, despite severe injuries, the majority of children injured by ATVs continue to operate these vehicles with no modification to safety behaviors.[11]

Although the North Carolina ATV legislation might have a greater impact in the future, it may not be sufficient. Many children continue to suffer serious morbidity and mortality despite ATV regulations. Over a 16-year period, the pediatric ATV mortality rates were compared between the 26 states with the highest ATV mortality rates and all other states. There was no difference between groups with regard to minimum age requirements and safety certification.[12] For example, Utah legislation prohibits children who are younger than eight years old from driving an ATV. Despite these safety measures, 25% of all injured children in Utah who were driving an ATV when injured were younger than eight years of age.[13] The American Academy of Pediatrics strongly suggests the passage of legislation in all states prohibiting the use off-road vehicles by children younger than 16 years.[14] Studies confirm that four-wheel vehicles are likely to be dangerous in the hands of immature or unskilled operators less than 16 years of age.[15] Focus groups report engine size restrictions, such as those used in the North Carolina law, are ineffective.[16] Licensing, training requirements, improved law enforcement, parental liability, and messages emphasizing the consequences of ATV use may be effective strategies for pediatric injury prevention.[16]

Although the Trauma Registry and Medical Examiner data captured those who were significantly injured and sought medical attention or were killed by ATV collisions, the data did not include non-trauma center medical evaluations or patients seen at the one North Carolina Level III Trauma Center. Future studies may be more encompassing and extend our understanding of the impact of state ATV legislation by following the time course of morbidity and mortality associated with ATV use. **NCMJ**

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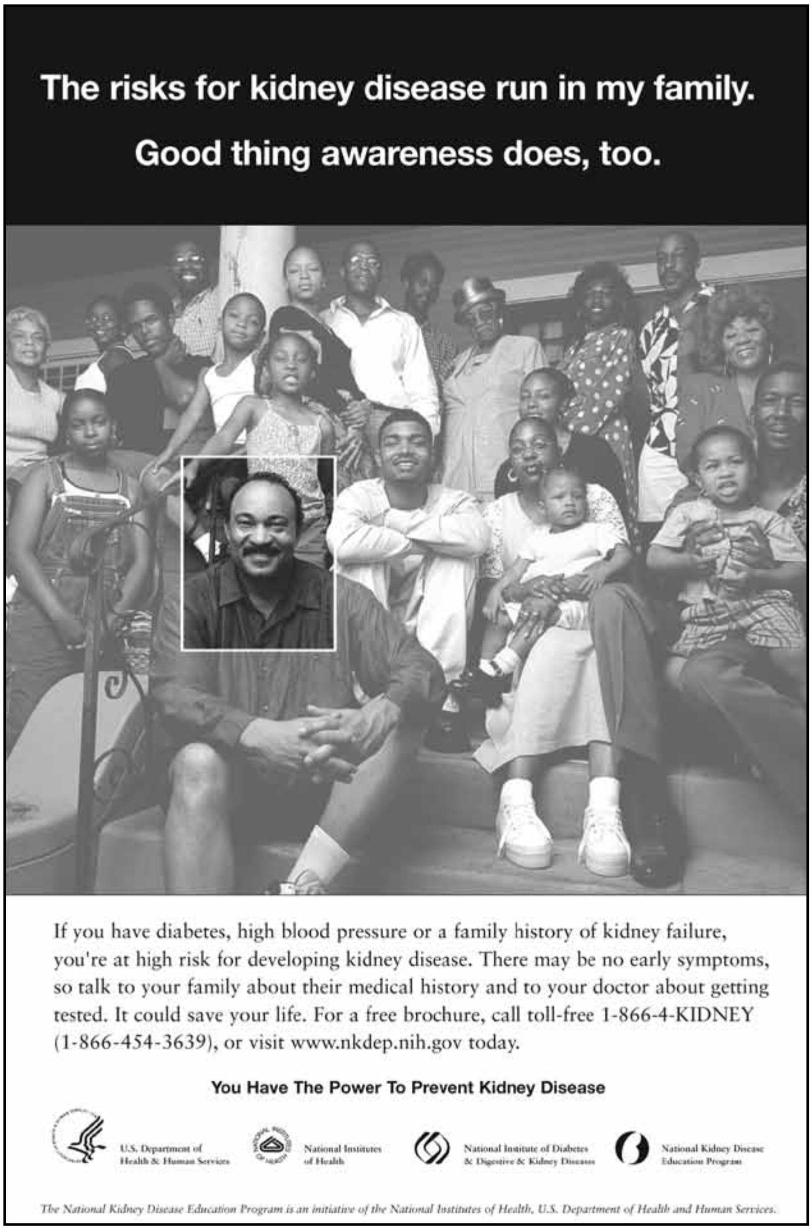

The Kidney Education Outreach Program's Community-Based Screenings:
Participants' Demographics and Screening Results

Donna H. Harward; Andrew S. Bomback, MD, MPH; Caroline E. Jennette, MSW; M. Ahinee Amamoo, MS; Ronald Falk, MD

Abstract

Objective: *To outline the Kidney Education Outreach Program (KEOP) screening protocol, to describe the context in which these chronic kidney disease (CKD) screenings were administered, and to report the characteristics and screening results for participants from October 2005 to September 2008.*

Methods: *A cohort of 1,742 people participated in targeted, free, community-based CKD screenings. Screenings included a self-report questionnaire regarding sociodemographic information, lifestyle behaviors, and personal and family health history. This survey was followed by urine dipstick testing for proteinuria and microalbuminuria.*

Results: *Medical histories were provided by 1,694 individuals: 1,522 through the complete questionnaire and 172 through an abbreviated questionnaire that differed principally in lack of information on family history of disease. Urine samples were collected from 1,706 participants. The mean age of screening participants was 54 years old; 70% were female, 50% were African American, and 13% were Latino. More than 40% of subjects were obese. Roughly one-quarter (23%) had been diagnosed with diabetes mellitus and about half (47%) had been diagnosed with hypertension. Twenty-four percent reported a family history of kidney disease. While 60% of the participants tested positive for microalbuminuria, less than 4% of these persons had ever been told they had kidney disease.*

Limitations: *Lack of confirmatory testing with a serum creatinine (and estimated glomerular filtration rate) or, alternatively, with a 24-hour urine collection for creatinine clearance and protein excretion; no standardized follow-up for screened participants.*

Discussion: *The KEOP targeted screenings disclosed a high prevalence of known risk factors for CKD—diabetes mellitus, hypertension, obesity, advanced age, and family history of kidney disease. However, despite these factors, less than 4% of screened participants were aware of a diagnosis of CKD.*

Keywords: *chronic kidney disease; screening; Kidney Education Outreach Program (KEOP)*

Chronic kidney disease (CKD) is defined by the National Kidney Foundation as a progressive loss of kidney function that can be identified by abnormal protein excretion in the urine and/or elevations in serum creatinine. CKD is a national public health problem whose prevalence continues to rise.[1,2] More than 26 million adults have early stage CKD and another 400,000 people are in the latter stage of the disease, often referred to as end-stage kidney disease (ESKD).[3,4] The disease burden is particularly prominent in North Carolina: approximately 940,000 (11%) of North Carolinians have early stage CKD, and North Carolina ranks 9th in the nation for statewide prevalence of ESKD (n=11,000).[5,6]

Unfortunately, CKD awareness is low among at-risk persons as well as among primary care physicians.[7-9] Treatment of CKD across all five stages, and its comorbid diseases (diabetes, hypertension, and cardiovascular disease), is very costly.[10] North Carolina's cumulative CKD-related health expenditures for 2007 were estimated to be around five billion dollars.[11] A 2008 report by the North Carolina Institute of Medicine Task Force on Chronic

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Kidney Disease acknowledged that CKD is a pervasive, expensive, and personally debilitating health problem for North Carolinians. The Task Force recommended the use of community-based awareness programs complemented by targeted screening for uninsured persons with diabetes mellitus, hypertension, heart disease, or any family history of kidney disease as important strategies to help reduce the burden of CKD.[12] Screening populations at high risk for CKD is essential in order to achieve consistent implementation of early therapeutic interventions that stop or slow the progression of the disease.[13]

Six years of national screenings administered by the National Kidney Foundation's Kidney Early Education Program (NKF-KEEP) included 2,495 North Carolina participants and served as the impetus for the University of North Carolina Kidney Center (UNCKC) to initiate the Kidney Education Outreach Program (KEOP) in 2005.[14] With the goal of raising awareness among North Carolina residents and primary care physicians about the major risk factors for CKD and the importance of early diagnosis and intervention, the KEOP has three primary components: (1) focus groups to ascertain perceptions about CKD that inform subsequent awareness activities, (2) interactive community conversations augmented by community-based media campaigns that use local citizens as spokespersons, and (3) free CKD screenings that target at-risk persons. Essential community-based partnerships with organizations, agencies, and lay leaders characterize the KEOP and help the program achieve sustainability and credibility through local ownership.[15,16]

North Carolina's highest ESKD prevalence rates are in rural counties.[6] Seventeen of these counties were selected as initial KEOP target counties. From October 2005 through September 2008, 35 screenings were held in six of these counties (Anson, Bertie, Edgecombe, Greene, Martin, and Montgomery) and in eight additional counties (Cabarrus, Davidson, Guilford, Hertford, Mecklenburg, Orange, Richmond, and Stanly) that invited the KEOP to participate in local health fairs or other community activities. The purpose of this article is to describe the KEOP screening protocol, the context in which these screenings were administered, and the characteristics and screening results of the KEOP's October 2005 through September 2008 participants.

Methods

Pre-screening Awareness Activities

Because lay person and primary care physician awareness about CKD is low, free KEOP screenings were preceded by several months of community-based activities that comprised interactive information sessions and local media campaigns that used local citizens as spokespersons. Focus groups were used to assess a community's preconceptions about CKD and explored whether residents perceived barriers to obtaining preventive or primary care. These preliminary activities emphasize active learning, are conducted in conjunction with local lay leaders, and have three foci: (1) to emphasize the primary risk factors for CKD: diabetes mellitus, hypertension, heart disease, and a family history of CKD; (2) to promote the value of being screened before clinical symptoms are apparent; and (3) to encourage at-risk residents to ask their primary care provider: "Hey Doc, How Are My Kidneys?"[17,18] Participation in these activities is voluntary, but high-risk populations are targeted through announcements and partnerships with local departments of health and social services, senior citizen councils, and faith-based organizations. Community partners host the information sessions to ensure locations that are familiar and accessible to residents.

Screening Protocol

Sites for the screenings included churches, hospitals, community centers, community colleges, senior citizen centers, and correctional institutions. Screenings performed after November 2007 continued to be hosted by local partners but were administered on the KEOP's mobile outreach unit. Any person age 18 years or older who could provide a urine sample and complete a questionnaire was eligible for screening. All screening activities and procedures were approved by the Office of Human Research Ethics at the University of North Carolina at Chapel Hill.

KEOP screenings were conducted by UNCKC staff members (physicians, nurses, educators, social workers, research technicians) and trained volunteers (medical students, citizens). After providing informed consent, participants completed a version of the University of North Carolina Kidney Center Screening Questionnaire. Participants completed either the 49-item document that asked participants to self-report information regarding sociodemographic information (e.g., age, education, race/ethnicity), lifestyle behaviors (e.g., tobacco use, alcohol consumption, exercise habits), and personal and family health history or an abbreviated, 19-item questionnaire that focused on key sociodemographic and health questions. The abbreviated survey was administered to participants who resided outside the host county. All questionnaires were read to participants to ensure standardization of documentation and to avoid potential discomfort and/or inaccurate reporting related to functional literacy issues.[19,20]

After completing either the full or abbreviated questionnaire, participants provided a spot urine specimen which was tested for proteinuria by dipstick (Chemstrip 10 MD Urine Test Strip [Roche Diagnostics]) and for microalbuminuria (Chemstrip Micral [Roche Diagnostics]). Proteinuria dipstick testing was performed for the entirety of the screening period; microalbuminuria testing began in July 2006, after the first 104 individuals were screened. On-site, risk for kidney disease was assessed with results from the urine tests. A dipstick value of one or greater for proteinuria (30 mg/dl or greater) and/or detection of microalbuminuria of ≥ 20 mg/l were considered abnormal.

At the completion of the screening, participants were given two copies of their test results and met individually with a UNCKC staff member for a review of their results. All individuals screened were encouraged to share their results with their primary care physicians. Individuals with abnormal test results were advised to follow up with a physician in one to six months, depending on the level of proteinuria and microalbuminuria detected. All screening result forms included a toll-free telephone number to ensure participants and physicians had access to KEOP staff to answer any questions about the screening or individual results. Participants who did not have a health care provider and/or health insurance were given a list of local clinics and primary care providers available to see such participants for follow-up care, including free clinics, federally-qualified health centers, or community health centers. Participants were also given educational materials such as pamphlets and brochures that explained the relationships between CKD, diabetes mellitus, and hypertension, as well as materials that promote active and healthy lifestyle choices.

Statistical Analyses

Statistical analyses were generated using the Stata statistical program, version 9.2 (StataCorp, College Station, TX, 2007). Descriptive analyses were used to characterize the screening population by sociodemographic data, health status, family history, and lifestyle behaviors. Mean values and prevalence rates were examined using Fisher's exact tests for all categorical variables and t-test for all continuous variables.

Results

Participants

From October 2005 through September 2008, 1,742 participants were screened through the KEOP. Medical histories were provided by 1,694 individuals: 1,522 through the complete questionnaire and 172 through an abbreviated questionnaire that differed principally in lack of information on family history of disease. Urine samples were collected from 1,706 participants. Forty-eight participants declined to complete a survey but consented for urinalysis. The screenings were performed in 14 North Carolina counties. By promoting the free screenings among at-risk populations, these targeted outreach activities captured a population with a higher than average risk for CKD.

The mean age of the screened population was 54 years, with almost 40% of participants aged 60 years or older. The vast majority of screened participants were female, and approximately half were African American. Fewer than 12 years of education had been completed by 20% of the participants. Of the 1,522 participants that completed the full questionnaire, 35% had smoked 100 cigarettes in their lifetime, and 8% had been diagnosed with some form of heart disease. Forty-two percent of the 1,694 participants who completed the surveys qualified as obese (BMI > 30kg/m^2) and nearly one-half and one-quarter of those screened had already been diagnosed with hypertension or diabetes mellitus, respectively. Family history of kidney disease was reported in 24% of screenings, while family histories of diabetes mellitus and hypertension were identified at far higher rates—66% and 78% respectively (see Table 1).

A large majority of the participants reported having some form of health insurance. Of the 1,694 participants who completed questionnaires (both the full and the abbreviated versions), only 53 (3.1%) answered "yes" to the question "Have you ever been told by a doctor that you have kidney disease?" (1,621 answered "no," eight answered "I don't know," and 12 did not provide an answer) (see Table 1). Notably, only 3% of the participants that tested positive for proteinuria and 4% of those that tested positive for microalbuminuria responded "yes" to this question.

Table 1.
Characteristics of the UNC Kidney Center KEOP Screening Population as of October 1, 2008

Characteristics	Overall (N=1,694)
Mean age, (Std)	54 (16.2)
Female	70.1%
Race/Ethnicity	
African American	49.5%
White	35.5%
Latino	12.8%
Native American	0.6%
Asian	0.5%
Other	1.0%
Less than high school education	20.7%
Smoke 100 cigarettes in life[a]	35.6%
Mean body mass index, (Std)	30 (14.4)
Health insurance	83.4%
Diabetes mellitus	22.6%
Heart disease[a]	8.4%
Hypertension	47.1%
Obese[b]	42.3%
Kidney disease[a]	3.1%
Family history of hypertension[a]	78.4%
Family history of diabetes mellitus[a]	66.4%
Family history of kidney disease[a]	23.7%

a. Data not captured for 172 participants who completed the abbreviated survey.

b. Obesity defined as BMI > 30kg/m^2.

Performance of Screening with Dipstick for Proteinuria and Microalbuminuria

Urine was collected from 1,706 participants—dipstick testing for proteinuria was performed on 1,706 samples, and microalbuminuria testing was performed on 1,497 samples. With dipstick testing for proteinuria, 194 (11%) samples were considered positive screens with values of one or higher. Microalbuminuria testing, using a level of 20 mg/l or higher as a positive screen, was considered positive for 902 (60%) of the urine samples. The vast majority of positive microalbuminuria tests were in subjects with 20 mg/l of microalbuminuria; less than 10% of these subjects tested positive for dipstick proteinuria (see Table 2).

Performance of Screening with Dipstick Among Diabetic and Hypertensive Participants

Of the 194 participants that screened positive for dipstick proteinuria, 37% were self-identified diabetics, and 61% gave a history of hypertension. Among the 902 participants that tested positive for microalbuminuria, diagnoses of both diabetes mellitus and hypertension were more likely to be present in positive screens. Specifically, 68% of self-reported diabetics had positive microalbuminuria screens, compared to a 58% rate of positive screens in non-diabetics (p=0.006). Similarly, participants with diagnosed hypertension had higher rates of positive microalbuminuria screens compared to participants without hypertension diagnoses, 64% vs. 57% (p=0.002) (see Tables 2 and 3 for further details on screening population characteristics). The level of diagnosed diabetes mellitus among those who screened positive was likely affected by how diabetic status was determined in this study. Participants were only categorized as diabetic if they had been diagnosed by their physicians. Participants who reported that they were "borderline" or "almost" diabetic did not qualify as a "yes" to the specific survey item, "Have you ever been told by a doctor that you have diabetes or that your sugar is high?" which may explain the low prevalence of diagnosed diabetes mellitus among the screened population.

Discussion

CKD is associated with premature mortality, decreased quality of life, and increased health care expenditures.[12] This growing public health problem, which now affects roughly 17% of the US adult population and over 900,000 North Carolinians, is well suited for population-based screening. The disease can often be identified early and progression can be halted or slowed with appropriate therapies, especially when implemented early in the disease when clinical symptoms are not yet apparent.

Not surprisingly, the KEOP's targeted screenings disclosed a high prevalence of known risk factors for CKD

Table 2.
Microalbuminuria Screen Results by Characteristics of the UNC Kidney Center KEOP Screening Population as of October 1, 2008 (N=1,497)

Characteristics	Normoalbuminuria (n=595)	Microalbuminuria[a] (n=902)	P-value[b]
Mean age, (Std)	55 (15.8)	54 (16.4)	0.303
Female	73.7%	66.3%	0.003
Race/ Ethnicity			
African American	43.0%	53.4%	0.003
White	39.2%	31.1%	
Latino	15.6%	13.3%	
Native American	0.9%	0.5%	
Asian	0.5%	0.7%	
Other	0.9%	1.1%	
Smoke 100 cigarettes in life[c]	35.6%	38.3%	0.317
Mean body mass index, (Std)	29 (6.8)	31 (17.7)	0.003
Diabetes mellitus	19.3%	26.5%	0.002
Heart disease[c]	6.1%	10.5%	0.007
Hypertension	43.7%	51.2%	0.006
Obese[d]	36.2%	46.5%	<0.001
Family history of hypertension[c]	76.3%	78.9%	0.291
Family history of diabetes mellitus[c]	66.5%	68.1%	0.580
Family history of kidney disease[c]	27.1%	24.0%	0.206

a. Microalbuminuria defined as urine albumin concentration >20mg/l (using semi-quantitative micral strips).

b. P-values reported are from Fishers exact test for all categorical variables and from t-tests for all continuous variables.

c. Data not captured for 172 participants who completed the short survey.

d. Obesity defined as BMI>30kg/m^2.

Table 3.
Detection of Kidney Disease in the KEOP by Two Screening Modalities

Screening Test	Negative Screen		Positive Screen		
Dipstick for proteinuria[a]	**Negative**	**Trace**	**1+**	**2+**	**3+**
N=1,706	n=1,106 64.8%	n=406 23.8%	n=171 10.0%	n=13 0.8%	n=10 0.6%
	n=1,512 (88.6%)		n=194 (11.4%)		
Microalbuminuria[b]	**Negative**		**20 mg/l**	**50 mg/l**	**100 mg/l**
n=1,497	n=595 39.7%		n=644 43.0%	n=178 11.9%	n=80 5.3%
	n=595 (39.7%)		n=902 (60.3%)		

a. For dipstick testing, trace denotes < 30 mg/dl, 1+ denotes 30-100 mg/dl, 2+ denotes 100-500 mg/dl, and 3+ denotes > 500 mg/dl.
b. 1,706 participants gave urine samples, of which 209 were not tested for microalbuminuria.

among the screened population, including diabetes mellitus, hypertension, obesity, advanced age, and family history of kidney disease. However, despite this confluence of risk factors, less than 4% of screened participants (53 of 1,694) were aware of a diagnosis of CKD. This result agrees with low awareness of CKD in the general population. Only 3% of participants in NKF-KEEP reported a history of CKD at screening despite 16% having an estimated glomerular filtration rate (eGFR) of less than 60 ml/min/1.73 m^2.[21] In the National Health and Nutrition Examination Survey population, less than 25% of subjects with moderately to severely decreased kidney function (CKD stages 3 and 4, eGFR 15-59 ml/min/1.73 m^2) were aware of CKD.[3] Given that more than half of the screened KEOP participants had detectable microalbuminuria, we expect that further diagnostic testing (for example, with serum creatinine or 24-hour urine creatinine measurements) will reveal kidney disease in greater than the 4% classified as having CKD.

The strength of the data presented here is that, in a relatively large and high-risk sample, community-based screening proved feasible. This type of community screening is not meant to diagnose disease, *per se*, but rather to identify individuals at high risk for disease and facilitate a more thorough workup for such individuals. Increased awareness of CKD and its associated risk factors is an associated benefit of community screening as well. Ideally, screening for CKD should include a detailed history accompanied by urine and blood testing; however, all of these components may not always be obtainable. The microalbuminuria performance in KEOP suggests that a fast, on-site urine screening test can identify individuals who would benefit from further evaluation. The low number of positive dipstick screens suggests that microalbuminuria should be preferentially used over dipstick proteinuria, if possible. We expect that there will be false positive results from the microalbuminuria dipstick testing, just as we are confident that there are false negative results with proteinuria testing. Given that the response to a positive screen in the KEOP and other screening activities is referral to a primary care provider, which imposes negligible risk and has the potential for tremendous benefit, we recommend the more sensitive test of microalbuminuria (notably, the NKF-KEEP screenings use this method as well).

A major limitation of these data is the lack of confirmatory testing with a serum creatinine (and estimated GFR) or, alternatively, with a 24-hour urine collection for creatinine clearance and protein excretion. The purpose of the KEOP is to identify subjects in need of further evaluation and not to validate specific screening tools. Subjects who did have positive urine screening tests (by dipstick or microalbuminuria) were referred to appropriate local health care providers, who likely did confirmatory testing. We do not have those results, however, and therefore can only speculate, as we have done here, as to how the screening tools in KEOP performed. It must be emphasized that CKD, by definition, is a chronic disease and can never be diagnosed by a single evaluation. Therefore, inclusion of serum creatinine testing at such screenings would not obviate the need for referral to a health care provider and at least three months of follow-up to truly diagnose CKD.[1]

Another limitation is that the screenings were done on a generally high-risk group, and therefore our results may not be applicable to the general population. However, CKD screenings may be more justifiable, in terms of cost and participation, in high-risk groups such as older persons and persons with diabetes mellitus and hypertension.[13] Implementation of health strategies, such as blood pressure control, avoidance of nephrotoxins, and dietary salt restriction, will likely have the greatest yield among such high-risk groups in terms of reducing the burden of CKD, and in terms of slowing and possibly halting progression to ESKD.

Still, we feel that the most crucial limitation of screening activities such as ours (and the original KEEP screenings upon which our activities were based) is the lack of standardized follow-up for the screened participants. This is a practical matter, as we can only provide information for formal primary care or nephrology evaluation and are not equipped to actually perform such evaluations. The NKF-

KEEP now provides the opportunity for participants to return on an approximately yearly basis for repeat evaluation. Yet this return for repeat testing does not entirely capture the optimal outcome from its screening, which is for a participant to become educated about disease risk and seek out a relationship with a local health care provider to further evaluate this risk. We plan, in the future, to institute a follow-up mechanism in the KEOP that not only ascertains whether screened participants seek local care after their screenings, but also which factor or factors in the screening (urine results, screening questions, discussion with staff) prompted this behavior.

Overall, results from the first 36 months of the KEOP reveal the feasibility of a targeted screening program to identify a significant number of individuals in need of further diagnostic evaluation for CKD. The program serves as a model that other communities, both at state and community levels, can follow in the fight to reduce the burden of CKD. **NCMJ**

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HEALTH REFORM IN NORTH CAROLINA

Senate Passed Health Care Reform: What It Means for You

Senator Richard M. Burr

This past Christmas Eve, the United States Senate passed legislation that will impact all Americans. This legislation will bring drastic changes to our health care system and greatly expand the federal government's role in it. So far, 43 physician organizations across the nation have come out in opposition to this bill, and while many of its long-term effects are yet to be fully understood, I want to take this opportunity to update you on what passage of this legislation means for you, your colleagues, and your patients.

This bill seeks to expand coverage to uninsured Americans by cutting Medicare, including cuts to benefits for seniors; significantly increasing federal spending and taxes at a time of record unemployment rates; and putting government bureaucrats between patients and their doctors. This bill also increases health care costs. It took a lot of closed-door negotiations and backroom deals to get this bill passed. In the end, Democrats secured the 60th vote needed when Majority Leader Reid included a provision that would have the federal government, and by extension all other states, fully fund the expansion of Medicaid in Nebraska. Despite the hours of debate and seemingly endless news coverage, we still do not know what the full ramifications of this bill's nearly 3,000 pages will be, and I fear we will be learning more and more about its negative and irreversible consequences for months and years to come.

What we do know, however, is that the Senate-passed bill squeezes providers, and it fails to address many of the most common and serious concerns I hear from health care professionals in North Carolina. A provision to provide a one year fix for the scheduled 21% cut in Medicare physician payments for 2010 was removed by Majority Leader Reid from the latest version of the bill. On December 19, the Senate passed a two month delay for the sustainable growth rate (SGR) cuts in a defense funding bill, but doctors and their patients deserve a permanent solution to this issue, not temporary patches that just push the problem further down the road.

According to the Centers for Medicare and Medicaid Services (CMS) Office of the Actuary, the bill funds hundreds of billions of dollars in new federal spending by relying on Medicare payment cuts, which are unlikely to be sustainable on a permanent basis. As a result, providers could find it difficult to balance office budgets and might be forced to end their participation in the Medicare program, thus jeopardizing access to care for seniors. The actuary's analysis also points out that these cuts could result in roughly 20% of Part A providers—from hospitals to nursing homes to home health agencies—becoming unprofitable within the next decade. Additionally, 15 million of the 31 million Americans covered by this bill will be Medicaid patients, and we know from years of experience that health providers are not reimbursed at the true cost of providing care to these patients.

In addition to being dedicated health care providers, you are all citizens, with concerns about how this bill will impact you and your family. All of us want to ensure that every American has access to high quality and affordable health care. All of us want to bring down the costs of health care. However, the CMS actuary predicts this bill will increase our nation's health care costs by almost a quarter of a trillion dollars over the next 10 years. This bill drastically increases federal spending, taxes health care plans, cuts Medicare, taxes life-saving medical devices and drugs, and increases the Medicare payroll tax. The impact of this bill on small businesses would also be devastating. Small businesses will be impacted by the employer mandate and other new and increased taxes in the bill. Moreover, the nonpartisan Congressional Budget

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Office's analysis indicates that this bill does very little, if anything, to lower costs for small businesses, and the individual market will see a 10%-13% premium increase. Health care reform should bring costs down, not drive them up.

Ultimately, the Senate passage of this bill is not the end of the road, but it is a large step in that direction. This bill will have to be reconciled with a very different House-passed bill which could mean that it will go to conference, and a compromise piece of legislation will be drafted that will go to both houses of Congress and must be passed by both Chambers, before heading to the White House to be signed into law.

As negotiations continue on this legislation, I will keep you informed of the impact it will have on you and all Americans.

Sworn-in to the United States Senate in 2005, Senator Burr has become a leading voice in the fight for meaningful, beneficial reforms to our nation's health care system, and against government run health care. He serves on the Health, Education Labor and Pensions Committee, the Energy and Natural Resources Committee, the Senate Committee on Veterans Affairs where he serves as the Ranking Member, the Armed Services Committee, and the Senate Intelligence Committee.

HEALTH REFORM IN NORTH CAROLINA

Health Insurance Reform and the Doctor-Patient Relationship

US Representative David Price

The hallmark of the American health care system is the doctor-patient relationship. In recent years, however, this relationship has come under threat from a confluence of factors within the system: the increasing number of Americans unable to obtain or afford health insurance, the lack of strong consumer protections within the health insurance industry, and the weak pharmaceutical plan and unpredictable physician reimbursement rates within Medicare, to name a few. Without real reform, we will imperil the strengths of our system and be stuck with its worst features: spiraling costs, instability, and inadequate care for far too many people.

Hundreds of meetings with physicians, patient advocacy groups, and other stakeholders; numerous town halls and roundtable discussions; and tens of thousands of phone calls, emails, and letters from my constituents have made one thing clear: the American people need a health care system that works for them. While they may differ on the details, nearly everybody agrees that our system should be based on the core principles of stable coverage, access to quality care, and affordable premiums and copayments. That's what health insurance reform is all about.

The Affordable Health Care for America Act (HR 3962), approved by the House in November, would achieve these core principles—without compromising the many strengths of our current system or adding to the national debt. For this reason, the bill has won the support of numerous stakeholder groups, including the American Medical Association (AMA), American College of Physicians, American Academy of Family Physicians, American College of Surgeons, American Academy of Pediatrics, the American Association of Retired Persons (AARP), the Consumers Union, the American Cancer Society Cancer Action Network, and many others.

The legislation recognizes that the first step to reform is ensuring that every American family has access to affordable health insurance. We know the cost of coverage is the major impediment for most uninsured, and for good reason. Between 2000 and 2007, North Carolinians saw their health insurance premiums increase 75% while their earnings rose only 14%. These skyrocketing premiums are pricing more and more people out of the health insurance market. Without reform, the Robert Wood Johnson Foundation estimates that more than 25% of Tar Heel residents won't have insurance 10 years from now. Losing access or delaying doctor visits means less preventative care, sicker patients, and a delivery system that provides "sick care" rather than "health care."

HR 3962 would address the access problem head-on. The bill would expand coverage options and broaden the risk pool through an insurance exchange available to Americans who are self-insured or employed by small businesses. The exchange would give individuals and small businesses access to the same lower group rates that larger companies have always been able to negotiate. For individuals and families that still could not afford insurance, the bill would offer further discounts in the form of affordability credits. All told, the bill would increase the coverage rate for legal, nonelderly residents from 83 % to 96%.

Second, the Affordable Health Care for America Act would expand access to care by addressing anti-consumer practices that have become standard in the insurance industry. The bill would prevent insurers from denying coverage on the basis of pre-existing conditions or selectively charging their policyholders different premiums based on gender, health status, or occupation. They would no longer be able to rescind or drop coverage when a person gets sick, or to cap the annual and lifetime amounts they pay

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for customers' health benefits and services. And they would be prevented from denying reconstructive surgery benefits for children with birth defects or injuries.

The bill also would eliminate the threat of bankruptcy due to medical expenses by requiring insurance companies to adhere to a standardized annual out-of-pocket spending limit. There would be new requirements on plans to ensure that they keep administrative costs down to 15% of premiums and pass along any savings generated to consumers. When insurers did need to increase premiums, they would be required to publicly disclose and justify the increases. These reforms would restore stability and trust in the health insurance industry and would give patients the confidence to seek preventative and timely care from physicians.

Finally, House Democratic reform efforts would address two major shortcomings in the Medicare system to strengthen the relationship between seniors and their doctors. The current Medicare physician reimbursement system—Sustainable Growth Rate (SGR)—is anything but "sustainable" and in fact has contributed to instability in health care both for providers and patients. The impending 21% fee reduction would result in rates that don't even cover providers' costs of care. HR 3961, the companion to the House health insurance reform legislation, would repeal the pending fee reduction and replace SGR with a new, more stable system, ending the cyclical threats of ever-larger cuts followed by 11th-hour, short-term fixes.

The House reform legislation also would fix a major flaw in the Medicare Part D drug program. Since 2005, Medicare enrollees have had the option to obtain drug benefits through Part D, but too many seniors lose drug coverage entirely for a portion of the year due to the so-called "doughnut hole." HR 3962 would reduce the size of the doughnut hole by $500 immediately and eliminate it completely by 2019. In the interim, it would require drug manufacturers to provide 50% discounts on brand-name drugs when seniors are in the doughnut hole.

The Affordable Health Care for America Act embodies the core principles I have sought—stable coverage, access to quality care, and affordable premiums and copayments. It is also consistent with the reform goals of the AMA. As the Association wrote in its letter of support for HR 3962, the bill "is consistent with our principles of pluralism, freedom of choice, freedom of physician practice and universal access."

The alternative plans offered by House Republicans would fail to achieve these goals. For example, the Republican substitute bill offered during House debate in November did not adequately address insurance affordability. The Congressional Budget Office (CBO) found that this version of reform would have reduced the number of uninsured by a mere 3 million, leaving 52 million Americans without coverage by 2019. It also lacked strong consumer protections and would have allowed insurers to continue to deny coverage for pre-existing conditions. Finally, the Republican substitute would not have closed the doughnut hole, forcing too many low-income seniors to continue choosing between groceries and prescriptions.

I know my Republican colleagues have some good ideas for health care reform, and the House-passed bill draws on some of them. For example, it includes interstate health insurance compacts to facilitate the purchase of individual health insurance across state lines and state incentive programs to implement alternatives to medical malpractice litigation.

Too much of the debate, however, has been ideological and accusatory, leveling charges of "socialism" and "government takeover," raising the specters of "death panels" and "rationing." This distorts and distracts us from the real issues. In this environment, it is especially important for doctors and medical organizations to make their voices heard, not only because of their experience but also because of their credibility: they stand above this political fray and can help the American people cut through the overheated rhetoric and confusion. We are on the threshold of major changes for the better for patients and their providers. We need to persevere, and we need to get it right.

David Price represents North Carolina's Research Triangle in the US House. He chairs the Homeland Security Appropriations Subcommittee and the House Democracy Partnership. Before he began serving in Congress in 1987, Price was a professor of Political Science and Public Policy at Duke University. He is the author of four books on Congress and the American political system.

POLICY FORUM

Putting People First: Services and Supports for People with Developmental Disabilities

> *People are considered to have an I/DD if they have a disability that manifested itself before age 22, is expected to continue indefinitely, and leads to substantial limitations...There are currently more than 100,000 people in North Carolina with an I/DD.*

COMMENTARIES

Introduction

POLICY FORUM

Putting People First: Services and Supports for People with Developmental Disabilities

Transitions are an important and necessary component in all of our lives. With each new transition we grow and begin to discover who we truly are as individuals. For children and adolescents, the most significant early transitions are the steps from elementary school to middle school, and then middle school to high school. As children grow up they are faced with the challenge of moving from living with parents to living on their own, and from dependency on others to dependency on themselves. For most of us, transitions can be an exciting and empowering time of our lives. However, for individuals with intellectual or other developmental disabilities (I/DD) transitions in life may be difficult and might require extra support and resources. This issue of the *Journal* focuses on transitions for people with I/DD, North Carolina's system for supporting individuals with I/DD, and the various issues surrounding caring for and providing health care to this group with varying levels of need and personalized care. The topic was one around which a Task Force of the North Carolina Institute of Medicine convened in response to a request from the General Assembly. The Task Force examined transitions for individuals with I/DD and many of the articles that follow are based on work done in the course of developing their report.

Individuals with intellectual or other developmental disabilities are diagnosed with I/DD if they have experienced a disability before age 22, the disability is expected to last indefinitely, and the disability creates limitations to daily living and/or cognitive skills. Additionally, in North Carolina, individuals with traumatic brain injury are also considered to fall within the I/DD category, regardless of the age at which they experienced the injury. Currently in North Carolina, there are more than 100,000 people living with I/DD.

Historically, North Carolina's system for providing care to individuals with I/DD has consisted of institutionalization or other out-of home placements. Over the past several decades, however, our beliefs and theories about providing care to people with I/DD have changed, and the system has transitioned towards a more community-based, family-centered model. Our goals have also changed; from merely assisting individuals with basic activities of daily living to promoting programs and support systems that enable individuals to live more independently and encourage them to become active citizens in their communities through employment, volunteering, and civic engagement. This emerging view is supported by many, including North Carolina's leaders in state agencies and many of the authors in this issue. However, our state has been slower than other states in its attempt to move people out of institutions and into the community. This is an area in which we can expect some growth in the years to come.

Currently North Carolina's system for people with I/DD is highly complex and consists of a wide array of services and supports that are usually based on an individual's level of need. Local Management Entities (LMEs) are generally the agencies charged with overseeing county or regional delivery system for individuals with I/DD but there are alternatives and options that are described in this issue of the *Journal* as recommendations from the Task Force.

By focusing awareness on creating a system of care that meets the needs of individuals with I/DD, we can help ensure that this population can live their lives to their fullest potential. High school graduation, college, employment, and meaningful relationships are all within reach and should be the norm, not the exception, for persons with intellectual and developmental disabilities. The commentaries contained in this issue of the *Journal* articulate how to make these goals a reality.

Thomas C. Ricketts III, PhD, MPH
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ISSUE BRIEF

Successful Transitions for People with Intellectual and Other Developmental Disabilities

Pam Silberman, JD, DrPH; James Bodfish, PhD; Adonis T. Brown; Leza Wainwright; Berkeley Yorkery, MPP; Jesse Lichstein, MSPH; Kimberly Alexander-Bratcher, MPH; Corey S. Davis, JD; Julia Lerche, MSPH; Mark Holmes, PhD

Robbie is a 24-year old living in Albemarle, North Carolina at Carolina Farms. He has his own bedroom, a roommate, an active social life, and he helps around the farm by working in a garden and feeding the animals. He has his own computer, DVD player, Wii, and every week he gets to enjoy social outings with other individuals living at Carolina Farms. They go to the movies, roller skate, dance, and out to eat at local restaurants. With the amount of independence and level of flexibility over his schedule, one would never guess that Robbie lives in a community built for individuals with autism.

Carolina Farms is a facility that allows individuals with autism to live and work independently on a beautiful farm. However, Robbie did not always have the opportunity of living at Carolina Farms. This is actually the third residential facility that he's been in over the past six years. During his first stays at residential facilities, he had five and six roommates living under one roof. Unfortunately, having so many roommates aggravated Robbie's aggressive behavior. Living in the group homes, he would have four or five episodes a day, but now at Carolina Farms, he has not experienced an episode in two years.

Transitioning Robbie out of his group home, which was operated by a nonprofit organization providing residential and day care services for individuals with autism, required countless hours and a number of case managers. Moving Robbie involved the nonprofit residential center communicating with the Murdoch Center (an intermediate care facility that is one of North Carolina's four state-run developmental centers) and the apartment supervised program at Carolina Farms. It took almost a year for the Murdoch Center to work with the Local Management Entity (LME) to get Robbie transferred over to Carolina Farms. Robbie's mother now says, "I'm proud of this transition. It was not easy to do and it took a lot time and cooperation between the LME, the Murdoch Center, the local residential nonprofit, and Carolina Farms—but it has been worth it. I knew he needed to be in a smaller group home at some point; Carolina Farms was a good opportunity. For any parent who has a child with a disability, start planning for their adulthood as early as possible. Things surprise you, and you turn around and your child is 14, then 18. I think it's important for children to grow up and live in a different community than their parents."

Transitions from one stage in life to another can be exciting. Think about when you started your first full-time job or when you purchased your first car or house. Yet, these transition periods can also be filled with stress.

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Transitioning from living with parents or other caretakers to living on one's own or from school to work can be difficult for anyone. These transitions to independence may be equally exciting or equally or more challenging for people with intellectual and other developmental disabilities (I/DD). However, key life transitions—from school to work, from an institutional to community setting, or the loss of a family member or other caregiver—can be particularly difficult for people with more significant intellectual or developmental disabilities.

People are considered to have an I/DD if they have a disability that manifested itself before age 22, is expected to continue indefinitely, and leads to substantial limitations in three or more of the following areas: self-care, receptive and expressive language, learning, mobility, self-direction, or the capacity for independent living or economic self-sufficiency. In North Carolina, people who have experienced a traumatic brain injury (TBI) are also considered to have an I/DD regardless of the age at which it occurred. There are currently more than 100,000 people in North Carolina with an I/DD.[1]

North Carolina offers a complex system of services and supports to people with I/DD. The Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (DMHDDSAS) is the lead agency charged with overseeing services provided to people with I/DD. Many people with I/DD receive their services and supports through their Local Management Entities (LMEs), county or regional governmental agencies that are responsible for managing the delivery of mental health, developmental disability, and substance abuse services. The LMEs typically do not provide services directly; rather, they contract for services and supports with private agencies.

While people with I/DD often turn to LMEs to identify appropriate services, many of the services and supports provided to people with I/DD are outside the DMHDDSAS system. For example, the Division of Medical Assistance (DMA) administers the Medicaid program that pays for and oversees some of the services and supports, including targeted case management, provided to people with I/DD. The Division of Health Services Regulation (DHSR) licenses many of the providers who offer residential and/or other habilitation services, including Intermediate Care Facilities for People with Mental Retardation (ICFs-MR) and other developmental disability group homes. The North Carolina Division of Public Health (DPH) provides services to younger children with special health needs (from birth through age two). Local Education Agencies (LEAs) are required, under the Individuals with Disabilities Education Act (IDEA), to provide services and supports necessary to help children and adolescents (ages 3-21) with disabilities succeed in school. People may also receive employment support or help with assistive technology or independent living through the North Carolina Division of Vocational Rehabilitation (DVR) and may receive cash assistance through the federal government's Social Security Administration.

The type of service that a person can receive depends, in part, on their age (school-aged or adult), their level of service needs, the funding agency, and where they live. Further, the availability and quality of services and supports varies across the state. Perhaps not surprisingly, the complexity of the current service and financing system makes it difficult for many people with I/DD and their families to identify and obtain needed services and supports. Services are often fragmented across agencies. In addition, payments for services come from different sources, each with their own eligibility rules. In her commentary in this issue of the *Journal*, Karen Stallings discusses the barriers that some people with I/DD and their families face in obtaining needed services and supports.

> ***...key life transitions—from school to work, from an institutional to community setting, or the loss of a family member or other caregiver—can be particularly difficult for people with more significant intellectual or developmental disabilities.***

People with I/DD need coordinated services and supports to help them through life transitions. Relative to others, people with I/DD may have fewer relationships with individuals to turn to for support. Interagency planning and coordination is particularly important during transitions, as is having a well-qualified workforce. Many young people with I/DD who age out of secondary school will need linkages to postsecondary schools, vocational rehabilitation, and their LME, as well as community organizations (e.g., churches, YMCAs) to ensure that they become active participants in their community. Older adults with I/DD may need to be linked to a variety of different services, supports, and housing if their aging caregiver or parent dies or can no longer provide necessary services or supports for them.

People who transition out of state developmental centers or private ICFs-MR will need access to an array of services and supports in the community consistent, in some cases, with a higher level of need. Regardless of the reason for the transition, people with I/DD need access to a comprehensive array of individualized services and supports to enable them to maximize their independence, productivity, inclusion, and self-determination in the community.

In July 2008 the North Carolina General Assembly (NCGA) asked the North Carolina Institute of Medicine (NCIOM) to convene a task force to study transitions for persons with I/DD from one life setting to another.[a] Specifically, the NCGA asked the NCIOM to identify barriers and best practices for successful transitions for adolescents leaving high school, including adolescents in foster care and other settings; people who leave a developmental center to live in a community-based setting; and others who live with aging parents or caregivers who can no longer provide services and supports. The Task Force was co-chaired by James Bodfish, PhD, director of the Center for Development and Learning at the Carolina Institute for Developmental Disabilities at the University of North Carolina at Chapel Hill; Adonis T. Brown, an independent living consultant and disability peer-advocate with EnVisioned Independent Living; and Leza Wainwright, the director of the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services. The Task Force also included 39 additional Task Force and Steering Committee members. The Task Force met six times between October 2008 and March 2009. The full report detailing the work and recommendations of the Task Force is available online.[b] Priority recommendations of the Task Force are presented in bold in this issue brief.

Transitions for Adolescents Leaving High School or the Foster Care System

Schools play an important role in helping all youth acquire the skills and knowledge needed to be successful as adults. This is particularly true for individuals with I/DD, who often face additional challenges when transitioning from childhood to adulthood. Students who have disabilities receive an Individualized Education Program (IEP) to help provide the necessary supports to assist them in succeeding in school. For example, students may need specialized instruction, assistive technology, or therapy services to help them address barriers to learning.

In today's economy, students must have a high school degree or higher to be competitive for work or eligible for postsecondary education.[c] School success is critically important for people with I/DD to gain the skills needed for self-support and to live as independently as possible. While the goal of the North Carolina public school system is to ensure that every student graduates from high school "globally competitive for work and postsecondary education and prepared for life in the 21st century,"[2] in 2007 only 49.5% of students with disabilities graduated with a high school diploma in four years.[d,3] This compares to 69.5% of all North Carolina students who complete high school within four years.[3] Graduation rates for students with disabilities vary widely by LEA and school. In 19 LEAs, fewer than 45% of high school students with disabilities graduated with a diploma. In contrast, more than 75% of students with disabilities graduated with diplomas in 16 LEAs. North Carolina's target is to have 70% of students who have IEPs graduate with regular diplomas by 2011.[e] More work is needed to improve the educational outcome of students with I/DD, including annual assessments, use of assistive technology, or other services to ensure students are maximizing their educational potential.

Individuals with I/DD who graduate or age out of secondary school need some mechanism to connect them with postsecondary schools, vocational rehabilitation, and LMEs to obtain postsecondary education, vocational training, workforce assistance, or other services and supports needed to help them become active participants in the community. North Carolina policy requires that the IEP team, including the student and his or her family, begin discussing transitions

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a. Section 10.15(s) of Session Law 2008-107.

b. The full report is available on the NCIOM website at http://www.nciom.org/projects/transitions/transitions_report.shtml.

c. At the time of the report, students with disabilities could participate in one of five courses of study: Career Prep, Tech Prep, College/University Prep, the Occupational Courses of Study (OCS), or the Extended Content Standards. Students in the first three courses (Career Prep, College Tech, and College/University Prep) must meet certain course, credit, testing, and performance requirements to graduate with a high school diploma. The OCS includes extensive career preparation classes (such as personal management, self-determination, job performance) along with academic courses. In 2004, 20% of students with disabilities participated in the OCS. Students in the OCS must complete course requirements, pass high school algebra, and have had competitive paid employment in order to graduate with a diploma. Students with more significant cognitive disabilities may enroll in the extended content standards (ECS). Students who demonstrate understanding of ECS course content graduate with a high school certificate. As of the 2009-2010 school year, the Career Prep, Tech Prep, and College/University Prep Courses of Study are not available to incoming 9th graders. These three courses of study have been replaced with the Future Ready Course of Study.

d. Unless otherwise stated, "children with disabilities" refers to all children with disabilities, regardless of the type of disability. The federal government recognizes 13 categories under which a child may qualify for special education including autism, deaf-blindness, developmental delay, emotional disturbance, hearing impairment, mental retardation, multiple disabilities, orthopedic impairment, other health impairment, specific learning disability, speech or language impairment, traumatic brain injury, and visual impairment.

e. A regular diploma certifies that a student has successfully completed all graduation requirements. A graduation certificate is issued when a student has completed their course requirements, but did not meet all graduation requirements (such as testing requirements).

when the child turns 14.[f] This is to ensure that all the plans and linkages have been created to ensure a successful transition out of high school. However, available state data suggest that North Carolina is not doing a particularly effective job in helping students link to competitive employment or postsecondary education settings.[4] A 2007 survey of students with an IEP who left school within the last year showed that only 58% of the students with an intellectual disability had been competitively employed, enrolled in postsecondary school, or both at some point in the past year. Thus, the Task Force recommended additional community-based skills training for students with I/DD, and greater interagency coordination to help them successfully transition out of secondary schools. In this issue of the *Journal*, Berkeley Yorkery and David W. Test offer their suggestions on how secondary education could be improved to better meet the educational and transition support needs for students with I/DD.

North Carolina's community colleges offer a free compensatory education program (CED) as part of the Basic Skills Program. CED is for individuals with intellectual disabilities who are not prepared to take academic or vocational classes. The CED's purpose is to "compensate" adults for the inadequate or lack of education they may have received earlier. In addition to these programs, North Carolina community colleges offer career and technical education courses; however, these courses often require prerequisites that students with I/DD may not be able to meet. **One of the Task Force's priority recommendations was to improve the educational and vocational programs available to people with I/DD in the community college system.** In addition, the Task Force explored what other postsecondary educational opportunities are available to people with I/DD. Aside from the course offerings at the community college system, there are few other postsecondary education options designed specifically for individuals with I/DD. Beyond Academics at the University of North Carolina at Greensboro is one of the more promising options. Joan Johnson and Terri Shelton discuss this program in their commentary. More of these types of postsecondary educational opportunities should be made available to people with I/DD.

In addition to the problems that youth face transitioning out of high school, youth with I/DD in the foster care system often face additional barriers transitioning to independent living. These children often do not have the traditional kinds of support—family, caring adults, mentors—that other youth have to help them through periods of transition. If identified early, children with I/DD in the foster care system can be connected to services and supports that can help them successfully transition from foster care into the community. Therefore, it is important to identify children with I/DD in the foster care system early so they receive services while in care and appropriate planning to ensure a smooth transition out of foster care.

Transitions for People Living in Large Congregate Living Arrangements to Smaller, More Independent Arrangements in the Community

People with I/DD, families, and advocates generally prefer smaller community settings to larger settings when offered appropriate supports and services.[5] Research shows that people with I/DD experience better outcomes in adaptive behavior, social participation, decision making, self-determination, and functional behavior when living in the community with appropriate and necessary services. [5]

Approximately 10% of North Carolinians with I/DD live in state developmental centers or private ICFs-MR with more than 16 individuals. People in the state developmental disability (DD) centers are, as a whole, significantly older than those residing in other settings,[g] and more than half have resided there for more than 30 years.[6] Most states, including North Carolina, have embraced the concept of providing community-based services and supports for people with I/DD, relying less heavily on state developmental centers or large ICFs-MR. In this issue of the *Journal*, Alexander M. Myers discusses the role that developmental disability centers may play in the future as they transition away from long-term residential care to providing other services and supports to people with I/DD.

While the state has articulated a policy preference to support individuals in smaller community settings, there has been less downsizing of large institutional settings in North Carolina than in many other states.[7] Past efforts to move individuals with I/DD from large DD centers or private ICFs-MR to smaller community settings have not been as successful in North Carolina as in many other states. Some of the barriers include lack of community capacity, communication difficulties between state developmental centers and LMEs, insufficient planning time with local case managers to arrange for appropriate community services and supports, and payment systems that discourage community providers from accepting people who have more intensive needs.[8] For example, North Carolina only pays for up to 60 days of targeted case management services for people leaving state developmental centers as opposed to the 180 days allowed by federal law. The Task Force recommended that the Division of Medical Assistance pay for up to 180 days of case management transition services for people transitioning out of state developmental centers and large ICFs-MR.

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[f] IDEA requires that transition services be a part of the IEP beginning with the IEP in effect when the child turns 16.

[g] Almost 70% of the people residing in North Carolina's developmental centers are older than age 45, in part because the state stopped admitting children into these large congregate settings in 1995.

Other states have been able to address these types of problems and, as a result, have been more successful in transitioning people out of developmental centers and ICFs-MR and into community settings.[9] In her commentary, Nancy Thaler describes how other states have helped improve the systems of services and supports for people with disabilities and successfully transition them from large institutional settings to smaller community environments. Her commentary, as well as her presentation to the Task Force, describe how the most successful states have had strong leaders who helped develop a comprehensive transition plan focusing on building community capacity rather than immediately closing facilities. **Thus, one of the Task Force's priority recommendations was to hire transition specialists with development disability expertise, at the state and LME levels, who have responsibility for developing systems to help people with I/DD as they are experiencing transitions. Additionally, the Task Force recommended that DMHDDSAS work with other appropriate agencies to develop a statewide transition plan that includes an analysis of the community services, supports, and funding needed to support successful transitions.** In her commentary, Patricia B. Porter describes the changes that would be necessary at the state and local levels to improve the system of supports and services to meet the needs of people with I/DD during transitions. In addition, Cindy Ehlers discusses the challenges that LMEs face in meeting the support needs of people with I/DD, as well as ways in which LMEs could do a better job working with other organizations in the community to develop a system of services and supports.

Transitions for Older Adults with I/DD and People with I/DD Living With Aging Parents

A large number of individuals with I/DD now live with their parents, siblings, or other adults. However, the ability of these individuals to provide the services and support needed by family members with I/DD decreases as the caregivers grow older.[10,11] Many people with I/DD living with older family members may need to change their living arrangements due to the death or diminishing capacity of their caregivers. Some families have never been connected to the developmental disability system and may not know where to seek help. The state needs to do a better job in reaching out to families of individuals with I/DD in order to provide them with information about available services and supports. In addition, parents or guardians of adults with I/DD are likely to need professional help to plan for their adult children's future. Advance planning is needed to ensure that the family knows how the financial, residential, security, medical, supports, legal, and social needs of the individual with I/DD will be met as the parent or caregiver ages or is no longer able to provide support. Susan Hartley describes the need for advance planning in her sidebar.

Cross-Cutting Issues

While there are unique challenges that people with I/DD face in specific transitions, there are some that are the same regardless of the cause of the underlying transition. People with I/DD need access to a comprehensive array of services and supports to help them during transitions. Leadership at the state and local level needs to be coupled with appropriate and flexible financing, case management services, and community capacity (e.g., housing, assistive technology, and supported employment) to ensure that there are sufficient services and supports to address the needs of these individuals. Additionally, North Carolina must ensure an adequate supply of well-qualified direct support workers and other professionals who demonstrate the competencies and person-centered values necessary to support people with I/DD in securing the quality of life that communities afford other people.

Leadership and Data: As noted earlier, North Carolina needs strong leadership at the state and local level with professional expertise in developmental disabilities. State leaders need to bring together people with I/DD, families, service providers, and other stakeholders to develop a statewide transition plan that includes policies and practices to facilitate transitions. Leaders at the local level need to establish linkages with appropriate agencies and service providers to facilitate successful transitions, identify gaps in services and supports, and build community capacity. Aside from state and local developmental disability leadership, successful transitions are contingent on having community capacity to address the needs of people with I/DD. However, it is difficult for North Carolina to develop a plan to expand community capacity or to know what services and supports are most needed without adequate data. **Thus, the Task Force recommended that North Carolina institute a waiting list system to capture information about the unduplicated number of adults and children waiting for services and the types of services needed.**

Financing: In 2006, North Carolina spent over $1.2 billion on services for people with I/DD, with 53% ($643.2 million) of the funding coming from the federal government, 41% ($493.7 million) from the state,[h] and 6% ($67.4 million) from local sources.[12] Medicaid is the largest source of funding for the I/DD service system in North Carolina, supplying 77% of total funding in 2006. (This includes both federal and state Medicaid funding.[12]) Medicaid helps pay for targeted case management, state developmental centers, ICFs-MR, and the Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities (CAP-MR/DD)

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[h] State funding includes state Medicaid matching funds, state augmentation of federal Supplemental Security Income (SSI) payments, and other state funds.

Waiver. The CAP-MR/DD waiver is a home- and community-based Medicaid waiver program serving individuals with I/DD who have a disability that would otherwise make them eligible to receive care in an ICF-MR facility. Medicaid also helps pay for other health-related costs for individuals who otherwise meet the eligibility requirements for the Medicaid program as well as nursing home costs for some frail adults with I/DD who need a nursing level of care. Non-Medicaid state funds are used to provide services and supports to people with I/DD who do not qualify for Medicaid. State funds can be used to pay for respite services, personal care, supported employment, long-term support, residential services, developmental therapy, and vocational programs.[13]

One of the biggest challenges the state faces is how to use its limited resources in the most equitable way possible in order to provide services and supports to people with I/DD. This is always an important consideration, but particularly so during tight fiscal years. This year, for example, the General Assembly reduced funding to the LMEs by 10% for each of the next two fiscal years.[i] This will mean that targeting existing resources to those most in need is imperative. Some states have begun to use assessment instruments to determine the relative intensity of support needs.[14-16] Data from these assessments can be used to set individual budget caps for waiver services, or to establish tiered funding levels to match the amount of resources an individual receives to their level of support needs. Data from these assessments can also be used to more appropriately pay providers, based on the case-mix of the individuals they serve. North Carolina has already begun to test the use of the Supports Intensity Scale (SIS) to assess the support needs of people with I/DD. More work is needed to use data from assessment instruments to make more rational resource allocations. **Therefore, the Task Force recommended that DMHDDSAS adopt a validated assessment instrument to determine the intensity of support needs, and use this information, along with other relevant information, to allocate resources.** In line with this recommendation, the North Carolina General Assembly directed the Division to continue implementation of the SIS assessment tool if the pilot project determines that the tool is effective in identifying intensity of service needs and types of services needed.[j] Rose Burnette, Christina Carter, and Leza Wainwright discuss the new assessment instrument being tested in different LMEs, as well as the Division's plan to develop new tiers of CAP-MR/DD waivers to more accurately reflect differing levels of support needs among people with I/DD.

Once the state develops a system that supports individual resource allocations, it can more easily move to consumer-directed budgeting. North Carolinians with I/DD are less likely to be involved in decision making about their lives than are people with I/DD in many other states. Consumer-directed budgeting helps support individual self-determination by giving consumers a certain budget and letting them decide what services and supports they want to purchase within this budget. North Carolina is beginning to test this model by offering the option to individuals who are part of the North Carolina Supports Waiver (a Medicaid home and community-based waiver program for individuals who are eligible for ICF-MR level of care, but who only need a limited amount of services). Other individuals with I/DD with more significant needs should also be given the opportunity for self-directed budgets. The state also needs to provide some flexible funding to assist people during their transitions. This can be used to pay for one-time expenses that are not normally covered through existing funding streams, such as security deposits, moving expenses, or household furnishings.

Community-Based Services and Supports: People with I/DD need access to a wide array of services and supports to help maximize independent living in the community. Their need for services and supports may change or intensify during transition periods. Individuals with I/DD may need access to crisis services, appropriate and affordable housing, assistive technology, trained health care professionals that are knowledgeable and willing to treat people with I/DD, educational and employment supports, accessible transportation, personal assistance in activities of daily living, and/or assistance in developing friendships and relationships. However, many communities lack important services needed to facilitate successful transitions. The Task Force recognized and supported the need to strengthen all types of community-based services. **Therefore, the Task Force recommended using existing funding to strengthen long-term vocational supports to help individuals with I/DD obtain meaningful employment.** The Division of Vocational Rehabilitation (DVR) within the North Carolina Department of Health and Human Services can assist people with I/DD who need more intensive support services to help them transition into competitive employment.[k] However, DVR's involvement ends once the individual, his or her employer, and the counselor and/or job coach agree that the person is performing his or her job successfully. Some individuals with I/DD need longer-term employment supports to help them maintain their employment. Funding is available to help pay for longer-term support services, but LMEs do not always help individuals with I/DD access these services. In this issue of the *Journal*, Michael Maybee and Jim H. Swain discuss

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[i] Section 10.19A(a) of Session Law 2009-451.

[j] Section 10.12(f) of Session Law 2009-451.

[k] Competitive employment is full-time or part-time work in an integrated setting (that employs people with and without disabilities), and which pays at or above the minimum wage, but not less than the wages paid to people without disabilities who perform the same or similar work. (34 CFR §363.6(c)(2)(i).)

the importance of long-term employment supports to help individuals with I/DD maintain competitive employment.

Individuals with I/DD may also have difficulty obtaining health care services commensurate with their needs. Just as it is for the general population, cardiovascular diseases and cancer are among the most common causes of death for people with I/DD.[17-19] However, national studies suggest that people with I/DD are more likely to have certain chronic illnesses, as well as secondary conditions that arise out of their disability, including epilepsy,[20] hypothyroidism,[21] gastroesophageal reflux disease, osteoporosis,[22,23] respiratory infections, dental disease, mental illness, or other behavioral health problems.[24] Although some studies suggest that many people with I/DD can access needed health services,[25] other studies—including a report by the US Surgeon General—identify shortages of health care professionals who are willing to treat patients with I/DD.[26] The reasons for this are many and varied, ranging from communication difficulties to lack of training and experience, poor patient compliance with treatment plans, and unwillingness of some providers to accept Medicaid.[27,28] Children have a particularly difficult time transitioning from pediatric care to adult services.[24,29] To address these problems, the Task Force recommended that health care professionals receive better training to address the health care needs of people with I/DD and that Community Care of North Carolina develop a pilot program to provide care and disease management to this population. In this issue of the *Journal*, Irene Jurczyk and R. Bruce Kelly describe the Mountain Area Health Education Center (MAHEC) Mini-Fellowship in Adult Developmental Medicine. In this program, MAHEC works with the Office on Disability and Health to develop medical curricula to facilitate the transition of care of youth with special needs from a pediatric to adult health care providers.

Skilled Staff: Case managers play a central role in working with people with I/DD and their families to ensure that the needs of the individual are being met. They must be properly trained and qualified to ensure that they are knowledgeable about developmental disabilities, the services and supports available in the community, available state and federal funding, and the legal rights of people with I/DD. While DMHDDSAS has identified certain case management competencies, it has not instituted a minimum training requirement (in terms of hours or standardized curricula), nor has it instituted a statewide competency-based exam.

Successful transitions are often dependent on having a well-qualified workforce that can provide the supports and services needed to help the person with I/DD live, learn, work, play, socialize, and retire in the community. Aside from an individual's family, direct support workers (DSWs) provide most of the day-to-day support for people with I/DD. In addition to providing direct services and supports, DSWs often facilitate connections to the community. DSWs are extremely important to the developmental disability system, yet there is no state-approved training curriculum or certification. Unlike certified nurse aides, who provide services to frail adults, DSWs are not required to complete a state-established curriculum or pass an approved competency exam. The Task Force determined that the skills and retention rates of DSWs should be improved. **Therefore, the Task Force recommended that the state develop and implement a plan to improve the competencies, skills, and retention of direct support workers and case managers.** In her commentary, Holly Riddle describes the role that DSWs play in meeting the support needs of people with I/DD and different options to increase the competencies, skills, and longevity of DSWs.

People with I/DD need a comprehensive, coordinated, and accessible system of supports and services to support them during life transitions. North Carolina can develop a more responsive, coordinated system of services and supports by increasing state and local developmental disability expertise and leadership, strengthening community capacity, and ensuring that case managers and direct support workers have the appropriate competencies to oversee or provide services and supports. By implementing many of the Task Force's recommendations, the state can help people with I/DD successfully transition from one life setting to another and live as independently as possible in the community. **NCMJ**

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North Carolina Developmental Disability Services and Supports:

Steps to System Improvement

Patricia B. Porter, PhD

The category of intellectual and developmental disability (I/DD) includes a large and diverse population. Individuals with cerebral palsy, intellectual disability, autism, severe learning disability, and those with other disorders that occur within the developmental period and meet the functional criteria are classified as intellectually or developmentally disabled. In North Carolina, I/DD also includes individuals who have suffered traumatic brain injury regardless of their age at the time of occurrence. Like those without disabilities, persons with I/DD aspire to achieve optimal health and wellness, but their needs extend beyond this. They want to choose where they live and who they live with. They want to be supported to obtain and maintain jobs that are satisfying and jobs that give them a competitive wage. They want access to education and recreation and the rights of full citizenship. Thus, the goals of the state-supported system of services and supports for its citizens with I/DD must be much broader and more comprehensive than health alone.[1]

In addition to medical and dental care, special therapies, behavioral intervention, assistive technology, and other specialized services, options for the I/DD population should include housing, work, recreation, and community participation regardless of where they live in the state or the extent of their disability. People with I/DD prefer these services be delivered as close to home as possible and, most importantly, they want to have the final determination of what services they receive and who delivers them. They want to count on a well-trained workforce and want to be able to review quality measures across service providers in order to make informed choices.[2] It is the responsibility of the state, in a transparent and fiscally accountable manner, to construct a system that assures safety, high quality service access, consistency, and equitable distribution of resources to address these needs in a way that is congruent with the shared philosophy, values, and mission of the disability group as well as being consistent with best practices.

North Carolina has a history of providing both a strong and robust system of services for persons with I/DD and a cadre of well-trained and experienced developmental disability professionals. These individuals have acted in partnership with recipients of services and their families, service providers, advocates, sister agencies, and other stakeholders to establish a solid infrastructure. That infrastructure should meet the goals of safety, physical and mental health, independence, productivity, authentic community participation, and a self-determined life for all citizens with developmental disabilities in our state. The state is also fortunate to have a broad array of dedicated providers of service, an exceptional Developmental Disabilities Planning Council, an independent protection and advocacy agency, a strong self-advocacy movement, and active

> ***We are a number of years past the initiation of the reform, and it is a good time to look at the current I/DD system of service outside of the construct of behavioral health. We should evaluate and shore up what works and change what does not.***

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partnerships with universities and community colleges. Our state developmental disability centers have responded to the need in our state by moving from life-long residential care to the creation of model demonstration programs for the most difficult-to-serve individuals. They serve as internship, research, and training sites for physicians, allied health professionals, educators, and counselors and as an education and training resource for direct service providers. In other commentaries in this issue of the *Journal*, authors describe extraordinary efforts ongoing with and on behalf of persons with I/DD across this state.

However there is no doubt that the recent fiscal crisis and subsequent state and federal budget cuts will have a dramatic impact on persons with I/DD and their families. This is further complicated by the fact that, unlike for behavioral health, private insurance rarely covers the broad array of I/DD services, and government is overwhelmingly the sole payer for this community. Questions have been raised as to whether the state system is sufficiently equipped to navigate the upcoming rough waters in ways which will best benefit individuals with I/DD who are in need of services and supports.[3]

Even before the current financial downturn, mental health reform in North Carolina brought significant changes in the system of services for people with I/DD. The Reform Act of 2001[4] declared the state's policy of advancing the dignity, rights, and responsibilities of citizens affected by disability and of maximizing their quality of life. The intent of the Reform Act was to move to a more locally-managed system with services delivered by the private sector. Implementation was left to planners in the Department of Health and Human Services (DHHS) who sought to structure a system with less dependence on institutions and more on community-based programs, and to increase consistency across the state to assure that individuals could access quality services regardless of where they lived. Private providers of services were also assured that their contracts with Local Management Entities (LMEs) would not vary from local program to local program.[5]

Prior to the reform, the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (DMHDDSAS) was structured into sections, each with its own particular focus: mental health, substance abuse, and developmental disabilities. Both community services and the operation of the state developmental disability centers were managed by the Developmental Disability Section. In 2001, DMHDDSAS moved to a cross-disability organizational model in which the sections were organized for certain functions irrespective of disability. This led to decisions that were based on the needs of one group, often resulting in a negative impact on other populations served by the Division. For example, behavioral health services for those with mental illness or substance abuse disease are, by definition, founded in a medical rehabilitation model with the ultimate goal of cure or recovery. Advances in medication management and adherence are major goals and outcomes are quantifiably measurable by limiting the need for hospital admissions and reduction in length of stay. However, the long-term care needs of persons with I/DD are far less episodic; therefore, a system focused on triage, determination of emergent or urgent care, and recovery is not appropriate for them.[6] While an I/DD system must include knowledgeable medical care, it must also support habilitation, life-long advancement of skills, and achievement of the ability to fully participate in a meaningful, self-determined life.

Prior to the reform, there was a coordinated organization from the state level through a regionally supported network of I/DD specialists to local programs (the former Area MHDDSAS Authorities) that was designed to assure seamless system management. The structure included a single portal of entry/exit at the local level which provided identifiable community access and a local point of contact that ensured that the needs and preferences of each individual would be assessed, therefore resulting in a multiagency process for person-centered planning and delivery of needed services. Well before the reform, the Area Authorities had been divested of service delivery for the vast majority of individuals with I/DD and were on their way to becoming local hubs with clear management and coordination responsibilities for the planning and delivery of services provided by the private sector. However, with the reform, rather than strategically assessing and revising while maintaining and expanding the successful components of the I/DD service system infrastructure as well as the many points of excellence throughout the state, much of the system was changed to fit a newly established behavioral health model. While some excellent results have been achieved in the health and behavioral health system as a whole, unintentional consequences have, to some extent, led to a lack of operational coordination, fragmented management, and disjointed accountability.[7] There is evidence that I/DD stakeholders are unclear about the ever-changing roles and responsibilities of state agencies and LMEs in their interaction with the critically important private service provider industry.[8]

We are a number of years past the initiation of the reform, and it is a good time to look at the current I/DD system of service outside of the construct of behavioral health. We should evaluate and shore up what works and change what does not. This must be managed with a "big picture" perspective; changing one part of the system will affect all parts.

System change decisions in North Carolina should be informed by a number of independent studies that have already been conducted to evaluate the impact of the reform on the I/DD service system.[9-11] These have been uniform in describing the I/DD system as fragmented and overwhelmed by the breadth and depth of the simultaneous "one size fits all" changes proposed in the reform effort. Studies also stress that thousands of persons with I/DD remain waiting for services.[3,8]

The purpose of this commentary is not to provide a comprehensive, research-based view of how the I/DD system should be structured in North Carolina; rather, it is to identify several key issues and to recommend changes to address these issues with the goal of system improvement. The issues listed below are found in some form in the studies referenced above; the recommendations are those I believe are the best and most practical solutions to these key issues.

Organization and Operation

The cross-disability organization of the Division of MHDDSAS described above has been further divided by action of the Secretary of DHHS this year. The Division of MHDDSAS will now focus on community services and supports and a new division has been established to focus on the state-operated facilities: the state psychiatric hospitals as well as the developmental disability, alcohol and drug treatment, and neuro-medical treatment centers. While the purpose of this as a mechanism to assure the improved operation of the facilities is understandable, it is conceivable that this may further fragment a system whose abiding mission has been to reduce the admissions of individuals to state facilities in favor of service delivery in home communities and to discharge individuals into communities prepared to receive and support them in a seamless and coordinated operation.

Recommendations:

- Establish a discrete unit focused on I/DD within the DHHS. North Carolina is one of very few states in the country without such an identifiable unit; many states have created separate departments of disability services or divisions of long-term care and disability services.
- Actively recruit and hire state-level I/DD leadership with state-level I/DD experience. The excellent and experienced I/DD staff currently within the Division are simply insufficient in numbers to manage the unique budgetary accountability and programmatic requirements of the system of services for I/DD. The mandate of these staff members would include establishment of measurable individual and system outcomes valued by persons with I/DD as well as quality standards for I/DD services based on national benchmarks.
- Re-establish a regional presence for I/DD. Expertise for training, monitoring, technical assistance, standards compliance, data collection and management, team building, information exchange, and accountability closer to the local delivery of service would maximize consistency and transparency, reduce miscommunication, and provide critical, identifiable, and accessible technical contact with individuals with I/DD and their families, LMEs, and other local agencies.
- Develop senior management positions within each LME with expertise in training, case management coordination, I/DD funding streams, desired outcomes, and best practices. These individuals would take the lead in the coordination of services and supports for persons dually diagnosed with mental illness and I/DD and would be the chief contact for persons moving from state and community intermediate care facilities to less congregate community settings.

Planning

Because of the diverse needs of the population and the extensive list of service options, service planning for I/DD differs from behavioral health and acute care in a number of ways. Key to this planning is comprehensive information on who is in need of services. For I/DD, waiting lists are stable and reliable; the majority of needed services are long-term in nature and change slowly over time. Issues such as recidivism, readmission to hospital, rapidly occurring crisis needs, and residence changes that impede the management of waiting lists are not issues for I/DD services. North Carolina no longer maintains and manages an active list of those persons eligible and waiting for I/DD services. Determination of numbers of persons in need of services by age and geographic location are currently based on national prevalence data which have been shown in the past to be inconsistent with actual need. There are currently no reliable figures for state and local planning, budget development, legislative requests, and preparation of Medicaid and Medicaid waiver applications.

Recommendations:

- Re-establish a systematic statewide I/DD waiting list system. During the 2009 session of the North Carolina General Assembly, session law was established to direct the Department of Health and Human Services to establish such a systematic waiting list for I/DD.[12]
- Employ waiting list data at the state agency and local management level for the purposes of development of clearly defined services that are responsive to actual needs, for fiscal planning, and for monitoring to assure qualified provider availability for all services.

Equitable Resource Allocation

As resources become more limited, it is critical to ensure that decisions on the allocation of available resources are made based on reliable and valid measures of relative intensity of need. That is, comparing the needs of each individual to the needs of all individuals with I/DD across the state for the purpose of ensuring justifiable and equitable allocation of resources. Many states have elected to employ intensity scale instruments for this purpose. These assessment scales can be used to achieve meaningful efficiency in the fair allocation of resources when reliably administered by well-trained individuals who are independent of the providers of service.

Recommendations:

- Establish a funding allocation formula based in a reliable and valid assessment of each I/DD-eligible individual that is consistently administered, and that identifies the intensity and complexity of the needs of each person compared to all other persons with I/DD regardless of the source of service funding. The selected assessment should be administered by well-trained assessors who are independent of the provision of services.

Assessment and Case Management

With the advent of reform, case management was transferred from the Area Authorities to the private sector. Because most individuals with I/DD need and receive a list of services and supports which may be most appropriately delivered by more than one provider, case management is a critically important service for people with I/DD. Currently, in order to avoid conflict of interest, the same private provider agency is not allowed to provide case management and also deliver services to the same individual. However this has proven to be a weak firewall. For example, case managers are put in the position of denying services requested from another agency then requesting services for their own service recipient from that same agency. The vast majority of case managers are conscientious and dedicated to the individuals they serve, but they have many incentives to draft service plans that may exceed the actual needs of the individual and no incentives to deny unnecessary services. They should be protected and supported with the training and authority that would come with independence and a better ability to distribute restricted resources fairly and equitably.

Recommendations:

- Eliminate potential conflicts of interest by ensuring that case management is independent of service coordination for persons with I/DD. This can be accomplished by returning it to the LMEs or by establishing independent provider agencies whose sole responsibility is case management.
- Assure that case managers have manageable case loads, are well-trained, and are well-compensated for the comprehensive responsibility they have with multiple vendors and individuals with complex needs.

It is not surprising that in the flurry of activity associated with mental health reform there have been unintended negative results. The unique situation of citizens with I/DD has made them particularly vulnerable. It is the responsibility of state government to organize and manage an effective and fairly compensated network that is programmatically and fiscally accountable and that proves optimally desirable for persons with I/DD, their families, and service providers. We must take advantage of the points of excellence already present in the system and build on those. I believe this can be achieved by following the recommendations set out above and that North Carolina can be justifiably regarded as a model system for citizens with I/DD. **NCMJ**

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North Carolina's Public System of Services and Supports for Individuals with Intellectual and Developmental Disabilities

Rose Burnette; Christina Carter; Leza Wainwright

The goal of North Carolina's public system of services and supports for people with intellectual and developmental disabilities (I/DD) is to promote independence and self-advocacy for the people they support. To achieve these goals the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (DMHDDSAS) endeavors to provide best practice services and supports designed to enable people with I/DD to live in housing of their choice, preferably their own home or with friends or family, and to encourage, whenever possible, meaningful employment. We believe that individuals with disabilities and the community as a whole are enriched when people with I/DD live and work in inclusive settings and are contributing members of society.

Three new initiatives are currently underway to further achieve these goals: (1) statewide implementation of a best practice model for providing crisis services to people with I/DD; (2) piloting a new, nationally-recognized assessment instrument to better identify an individual's need for services and supports; and (3) developing and implementing an array of home and community-based Medicaid waivers to meet the needs of people with I/DD in a more individualized manner.

NC START

Developed in 1989 by Dr. Joan Beasley as a model for providing community-based crisis intervention and prevention services to adults with I/DD and behavioral health care needs, the Systemic, Therapeutic, Assessment, Respite, and Treatment (START) model is a best practice which, based on preliminary data, indicates positive outcomes. Data are collected regularly to evaluate the effectiveness of the program. In 2008, the North Carolina General Assembly provided funding to develop and operate six START teams, and North Carolina became the first state to implement START on a statewide basis.

Two providers and three Local Management Entities (LMEs) are involved in implementing NC START on a regional basis across the state. RHA Health Services, Inc. operates two START teams under the management of the Western Highlands Network in the western part of the state and also operates two teams under the management of East Carolina Behavioral Health (ECBH) in the eastern region of the state. Easter Seals/UCP operates two START teams serving the central region under the management of The Durham Center. Each team is comprised of a psychologist and other qualified developmental disabilities professionals who work in collaboration with a psychiatrist. The teams provide direct services to individuals experiencing a crisis and provide consultation and technical assistance to other providers and families on methods to prevent and de-escalate crisis situations. An example of such a crisis

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may involve an individual who exhibits extreme behavioral disruptions including property destruction, aggression towards themselves or others and/or the inability to regulate their emotions and interactions with their environment. Each team also has access to a facility that can provide planned, short-term respite services for individuals whose behavioral needs create problems in obtaining other respite services and for emergency respite to address crisis situations.

NC START is designed to provide positive outcomes for individuals with disabilities as well as for the communities in which they live. At the individual level, NC START helps people achieve stability and remain living in the community by decreasing behavioral challenges and symptoms, thereby avoiding the use of hospitals or state facilities. For the community, NC START provides resources to increase the knowledge of how to address behavioral crises in the community and serves as a means of coordinating various community resources to meet the needs of people with I/DD and behavioral health challenges.

In April 2009, the new NC START teams began providing services. During the quarter ending June 30, 2009 they provided direct services to 158 consumers, including 316 days of respite care, and conducted 428 training events in the community.

New Assessment Tool

North Carolina is pilot testing a new tool to assess the service and support needs of individuals with I/DD. The new tool, the Supports Intensity Scale (SIS), was developed over a five-year period by a team of national experts and is endorsed by the American Association on Intellectual and Developmental Disabilities. The SIS is a multidimensional scale designed to assess support needs, determine the intensity of needed supports, monitor progress, and evaluate outcomes of adolescents and adults with I/DD. Unlike some previous assessment instruments, the SIS does not measure an individual's deficits, but rather focuses on the supports needed for the individual to fully and successfully participate in everyday life within a home and community environment. Assessment results present a graphic representation of an individual's support needs across six life-activity domains: home living, employment, community living, health and safety, lifelong learning, and social activities. It also produces a composite score reflecting an individual's overall intensity of support needs relative to others with I/DD. These results assist the team in developing a person-centered plan that identifies individualized supports that are responsive to the needs and choices of an individual based on what is important to and for this person to be successful.

The Division of MHDDSAS is piloting the use of the SIS in seven LMEs across North Carolina (see Table 1). The purpose of the pilot is to determine if the SIS provides sufficient information to accurately identify services and supports needed for individuals with I/DD across a variety of possible living arrangements—independent, family, small group home, large group home, and state-operated facilities—and to evaluate for Medicaid and state funding streams. In the pilot LMEs, licensed practitioners who have at least two years of experience working with adults and children with I/DD who are enrolled to participate in the Medicaid program conduct SIS assessments. Prior to conducting the assessments, the assessors receive 13 hours of SIS training; they must also take yearly refresher training. The pilot project began in April 2008. As the table below indicates, through December 14, 2009, 428 individuals in seven LMEs have received SIS assessments.

Based upon the assessment of these 428 individuals, the Division believes that SIS does provide information that is very useful in developing plans to serve and support individuals in a more personalized manner. The pilot shows the instrument provides valid results regardless of the individual's living arrangements or source of funding. The Division is currently working to develop strategies to address some of the challenges to statewide implementation that the pilot project has identified, including the cost of the assessment instrument itself, the limited number of

Table 1.
Supports Intensity Scale Pilot Progression

Local Management Entity	SIS Assessments Completed as of December 14, 2009	Number of CAP-MR/DD Waiver Participants Ages Ages 16 and Older	Percentage Completed
Durham	64	216	30%
ECBH	33	354	9%
Five County	56	206	27%
Guilford	28	355	8%
Mecklenburg	117	602	19%
Sandhills	122	391	31%
Smoky Mountain	8	479	2%
Total	**428**	**2,603**	**16%**

licensed professionals who are qualified and willing to administer the assessments, and family resistance to the time needed to accurately conduct the assessment. The North Carolina General Assembly has required the Division to report the results and recommendations from the pilot to the Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services and the Appropriations subcommittee by May 1, 2010.

Tiered Home and Community-Based Waivers

The primary funding source for services and supports to people in North Carolina with I/DD is Medicaid funding provided through Home and Community Based-Services (HCBS) waivers. Medicaid regulations permit states to apply for HCBS waivers authorized under section 1915c of the Social Security Act which allows the state to deliver community-based services to individuals who would otherwise be eligible for institutional care. The regulations permit states to target waivers to specific populations, modify income and asset limitations for those authorized under the state's Medicaid plan, waive parental and spousal income and asset limits under certain circumstances, and limit the number of individuals who may participate in the waiver based upon the number approved by the federal government and the state's available funding.

In North Carolina, HCBS waivers are called Community Alternatives Programs (CAP). North Carolina has operated a CAP program for individuals with I/DD, the CAP for persons with mental retardation/developmental disabilities (CAP-MR/DD) waiver, for many years. In 2007, the General Assembly directed the Department of Health and Human Services to replace its existing CAP-MR/DD waiver with a series of "tiered" waivers designed to serve more people through this funding source by controlling growth in the cost of services. Per the direction of the General Assembly, North Carolina will eventually operate four individual CAP-MR/DD waivers, each with different benefit packages and different upper limits of services and supports available to waiver recipients.[a]

On November 1, 2008, North Carolina began the implementation of a tiered approach by launching the first two waivers, the Supports Waiver that offers benefits up to $17,500 annually, and the Comprehensive Waiver that offers services and supports costing from $17,501 to $135,000 on an annual basis. The array of services and supports available in the two waivers is similar, and when a service or support is included in both waivers, the service definitions and requirements for that service are the same in order to eliminate confusion for providers. For example, both waivers offer the opportunity for recipients to receive supported employment services. The supported employment service looks identical in each waiver, but someone on the Supports Waiver would likely receive less supported employment services than someone on the Comprehensive Waiver might receive. The Supports Waiver served approximately 187 people in SFY 2009. The plan is to provide services to approximately 1,000 persons through the Supports Waiver in SFY 2010. Over 10,000 individuals currently receive services through the Comprehensive Waiver.

The Supports Waiver, also known as the Tier 1 Waiver, offers services and supports to individuals living in their own home or with family. The Supports Waiver is not appropriate for individuals living in group homes or other out-of-home living arrangements. In most cases, individuals supported through this waiver have access to significant natural supports from family members and the community and may experience less intensive needs than someone served through the Comprehensive Waiver. The Supports Waiver provides an option for individuals to participate in Self Direction. Self Direction is a national movement in the I/DD community designed to empower individuals to become active participants and managers of the services and supports they receive, as well as to become active community citizens who have valued social roles in the community. The principles of Self Direction embedded in the Supports Waiver include:

1. *Freedom* to choose services/supports and the staff that provides them;
2. *Authority* over how services and supports are delivered;
3. *Support* for organizing services/supports in a manner that may be unique to the individual;
4. *Responsibility* to manage public funds appropriately; and
5. *Confirmation* that individuals with disabilities must be a major part of the design of the service system.

The Self Direction option in the Supports Waiver will become available November 1, 2009. At this time, we do not know how many recipients will choose to elect this option.

The Comprehensive Waiver offers services and supports to individuals whose waiver needs can be met with services costing less than $135,000 per year. It can serve people living in their own home or with family, as well as individuals living in group homes, alternative family living settings, and other out-of-home living arrangements. In most cases, individuals who receive this level of waiver funding have more intensive medical and/or behavioral needs than individuals who receive funding from the Supports Waiver.

In accordance with the General Assembly's direction to create four tiers of waivers, plans are currently underway to amend the Comprehensive Waiver to create two additional waivers. The new Tier 2 waiver will offer services and

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[a] Piedmont Behavioral Health, the LME serving Cabarrus, Davidson, Rowan, Stanly, and Union counties, operates its own HCBS waiver for individuals with I/DD, known as the Innovations Waiver. The direction to implement tiered waivers does not apply to the Innovations Waiver.

supports costing between $17,501 and $45,000 annually. This new waiver will also offer the Self Direction option. The Tier 3 waiver will provide services and supports costing between $45,001 and $75,000 annually, and the Comprehensive, or Tier 4 waiver, will serve individuals with the highest level of need for services and supports costing between $75,001 and $135,000 per year. We anticipate the two new waivers and the revised Comprehensive Waiver will be implemented sometime in 2011.

North Carolina's public system of services and supports for people with I/DD continues to advance initiatives to promote independence and self-determination for people supported by the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services. These strategies support that goal by using best practice approaches designed to support people with I/DD to live in homes of their choice, to participate in meaningful employment, and to become contributing members within their community. These fundamental tools provide the necessary structural framework to effectively provide assessment, planning, and strategic interventions that promote positive outcomes and support meaningful lives. **NCMJ**

Constructing the New Service Paradigm:

Responding to Today's Challenges

Nancy Thaler, MHOS

In the 1970s, the only service available for people with intellectual and developmental disabilities (I/DD) and their families was placement in a large institution. Today, services are predominantly community-based. In just one generation our thinking about people with I/DD has been transformed. Today, nine states and the District of Columbia have no publicly-operated institutions dedicated to people with I/DD. In 2006, states spent over $43.83 billion on services to people with I/DD. Of that amount, $35.5 billion was targeted to community services.[1]

Even when institutions were the only service option available, they were an undesirable alternative. Reluctant to send their children far from home, many families simply struggled on without public support. However, with the introduction of community group homes in the 1970s, families were provided a new and more attractive alternative. As the demand for community group homes began to grow, states felt increasing pressure to expand services. In 1981, Congress passed Section 1915(c) of the Social Security Act which created the Home and Community-Based Services Waiver program, also known as the Medicaid Waiver program. This program allowed Medicaid funding, which previously had been available only for institutional services, to be used for community services as well. Thus, the Medicaid Waiver program fuelled service expansion.

The Paradigm Change of Tomorrow

By the late 1990s, states were discovering a limit to their capacity to expand group homes. The aging of the nation's baby boomers was increasing both the demand for services and the competition for caregivers, while the number of people in the workforce available to work as caregivers was not growing commensurately. Frustrated by long waiting lists for services, in some states people began to file lawsuits. The then current paradigm had been built on a residential model in which a service provider had 24-hour responsibility for all aspects of the person's life. But the high demand for services and the legal pressures compelled states to look for a solution—and that solution was to expand supports provided to people living at home with their families.

States had been providing family support services for many years, but those programs were often minimal and were generally limited to respite care and, in some cases, a small financial stipend. Now states realized that the federal Home and Community-Based Waiver program could also be used to provide services in a person's home. This meant that states could expand family support programs to cover a full range of services in addition to respite care, including day programs, therapies, family training, environmental modifications, and in-home support.

As a result of this expansion in home-based services, we are now witnessing another transformation in our state service systems. By 2007, the majority—a full 56%—of people receiving services from state developmental disability service systems were not living in residential programs but with their families.[2] Given the demographic and economic realities of our time, we will likely see this shift toward home-based services continue to grow.

> ***By 2007, the majority...of people receiving services from state developmental disability service systems were not living in residential programs but with their families...we will likely see this shift toward home-based services continue to grow.***

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New Challenges

The shift in the service paradigm, to one in which adults with disabilities will live with their families well into their adult years, presents new challenges to states. What is the role of the state and service providers when family members are the primary caregivers? Where does the role of the family end and that of the service system begin?

Adults with developmental disabilities generally cannot declare their independence or strike out on their own; their everyday dependency on family members makes it difficult for them to rebel in the same way that other children do. A family that is caring for an adult child with a disability at home faces the challenge of helping that son or daughter become as self-sufficient as possible, while at the same time providing care and support to them—they are liberating their child even as they continue to be the primary support for that child. Families with children without disabilities do not face such a challenge; a family that is caring for an adult child with a disability may need help not only in meeting this challenge but also in recognizing it.

The National Core Indicators Project

What do we know about people living with and getting support from their families? The National Core Indicators (NCI), a project of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Resource Institute (HSRI) has been collecting data on the performance of service delivery systems for people with I/DD since 1997. An annual survey of individuals and families receiving services in each participating state provides reliable data on a wide array of topics, including individual and family demographics, personal outcomes, and system performance.

The 2007 National Core Indicators Adult Family Survey Final Report – April 2008 reveals a great deal about people with I/DD living with families.[3] The 25 states that participated in the NCI project in 2007 reported that the annual income of 50% of families was under $25,000, 62% of family caregivers were over the age of 55, and some families who had a family member with a disability living with them felt isolated and cut off from their communities. People with a disability living with their families reported being less lonely, happier, and liking where they were living more than people living in residential settings. However, the report also tells us that people living with their families are not as likely to recount having a best friend, not as likely to be able to see friends when they want to, and more likely to say they don't have any friends. Compared to adults in other residential settings, people living with families are also less likely to have had a physical exam in the past year, less likely to have had a gynecological exam in the past year (if female), and less likely to have been to the dentist in the past six months.

The Importance of Family

The family is the core unit of our society. Within the nurturing environment of family life, we develop our identity and our self-confidence, we perfect the ability to get along with others, we discover our capacity to love. Home is the safe harbor within which we can grow. Unfortunately, sometimes families cannot meet the need of every family member. Extended family, friends, and community services, such as schools and medical facilities, make up a larger support system which stands a greater chance of meeting these needs.

It is also true that home can be a place where family members can be at risk of harm. Protective service statutes and reporting systems have evolved in response to this unfortunate reality. People with developmental disabilities are often ill-equipped to protect themselves, to seek safety, or to report abuse.

What is the role of the state and individual providers when family members are the primary caregivers? Can we ensure that people living with their families have a say in decisions that affect them, that they get routine medical attention, that they have opportunities to make friends outside the family, and that they have a good diet and get exercise? Can we facilitate a life outside the family home—one that includes a job and friends? Can we assist in resolving conflicts as the family struggles to meet everyone's needs? Can we protect individuals with developmental disabilities from harm? The answer to these questions is of course—"we must." State agency personnel and service providers must learn about the complexity of family life for parents and other family members and for the individual with disabilities, and must be prepared to serve them appropriately.

Providers and support coordinators need training to understand the experience of people with disabilities and their families, and they must develop the skills needed to negotiate the complex and ambiguous territory of family dynamics. In situations of conflict, they must learn to stay focused on the point-of-view of the person with a disability, even as they work to meet the needs of the whole family. Caregivers and supporters must learn to collaborate with families—as well as to respectfully challenge them on behalf of the person with a disability. They must learn to recognize stress in the family and to anticipate a family's need for assistance.

And what happens when the parents of adults with disabilities can no longer provide supports? In the first half of the 20th century, when parents began to consider their own mortality and sought to plan for their child with a disability, they placed the responsibility on the siblings if they were present. But as the service system changed in the latter half of the 20th century, parents shifted their expectations to the public system and often spoke of not wanting to burden their other children with the care of the disabled sibling. But in this area, too, the paradigm is changing. As more and more children with and without disabilities grow up together at home and in schools, siblings or close relatives are increasingly taking an interest in the sister, brother, or cousin with a disability and want to be involved. If, once the parents have passed away, the same supports can continue for other family members willing to open their homes and provide support, we may find far more siblings willing to be the primary caregiver for their brother or sister with a disability.

Individual and Family Control Over Services

In addition to the demand for expanded services, people with disabilities and their families also expect to have more control over the services they receive. The authority to hire and fire caregivers and to control a budget are the essential elements of "self-directed services." As of January 2009, 13 states offered individual budgets and consumer control for at least some individuals and 11 states had a consumer-directed option available to a small number of people in a limited geographic area as a pilot project.[4] Studies conducted of self-directed services demonstrate both high levels of satisfaction and significant cost savings as people take more responsibility for how their resources are utilized.[5]

In the developmental disability field, consumer-directed services is a necessary component of what is referred to as the "right of self-determination"—the right of people to control where and how they live their lives. People and families who rely on publicly funded services have often found their capacity to control their lives hampered by inflexible service provider rules and state service systems.

Giving people the ability to hire and fire support staff opens the possibility of hiring people who might otherwise not work in the human service system—neighbors, friends, and even family members. This option expands the pool of people available to provide supports, in addition to also opening up many possibilities for people with disabilities and their families. Self-directed services are also a partial solution to the shortage of available workers to provide services. In addition, having control over a budget has enabled people with disabilities and their families to use services when they need them, to "save for a rainy day"—i.e., a time when family situations demand a higher intensity of services.

Self-directed services require that states have necessary infrastructures in place to determine appropriate levels of funding, to assure that IRS rules are adhered to, to make certain that caregivers are appropriately trained, and to guarantee accountability for funding. Above all, state developmental disability agencies are responsible for overseeing the quality of services that are being provided and ensuring that individuals with I/DD are living the lives that they want to be living.

Guidelines for Creating the Service Paradigm to Support People and Their Families

Our state service systems will continue to maintain out-of-home residential service options. But, recognizing that families are the primary support system for people with disabilities, we must design the service system with this fact as a core concept. This will likely require instituting new practices, developing new training, establishing new standards for services, and thinking differently about the provision of services. To achieve the goal of providing supports for individuals with I/DD living at home, we will need to:

- Start planning early with the person and their family. Connection to the service system and the benefit of some basic services early on will give families confidence that the system will be there for them throughout the future. Early contact can facilitate the transition from school to adult life and a job.
- Think of family in broad terms and build relationships with the entire family network: include parents, siblings, grandparents, other relatives, and friends.
- Focus both on the desired outcomes of the person with a disability and on the needs of all the family members. Remember that a person with a disability lives in the context of their family. Be prepared to negotiate and facilitate during service planning sessions in order to identify and reconcile the needs of the person with the disability with those of the whole family.
- Remember that adults need relationships and activities outside the home, including:
  - Employment—a competitive job at a competitive wage is the pathway to independence and community participation.
  - Friends—making friends and spending time with them provides both fun and support.
  - Organizations—participation in self-advocacy organizations offers an opportunity to meet others with similar interests and concerns and to solve problems together.
  - Community—participating in community life by joining community organizations, attending events, and volunteering expands a person's network of support.
- Use innovation. Be prepared to offer individuals and their families the opportunity to direct their own services, control an individual budget, hire friends and relatives, and explore home ownership.
- Develop and maintain strong support/coordination services to assure responsiveness to families. Limit the size of the support coordinator's caseload. Offer training in family systems and provide meaningful supervision. The support coordinator's role is a high-stress position but it is the one most critical to preventing crises or breakdown in the family support structure.

The New Question

Service systems in the 20th century evolved in response to events, pressures, and opportunities. But rapid development prevented leaders from paying adequate attention to determining the service paradigm and to building the infrastructure necessary to support it. In 2009, we can see that another change is upon us. We know that for the next generation the role of families will be essential in providing support for people with I/DD. Ultimately, the question is not whether people with I/DD will be living with and relying on their families for support—they most certainly will. Rather, the real question is whether the person with a disability and their family will continue to struggle, and sometimes fail, alone, or will that adult son or daughter with a disability have a good and successful life because of the supports we have planned for and made available to them and to their families? **NCMJ**

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Filling the Gaps through Partnerships, Collaboration, and Flexible Funding

Cindy Ehlers, MS, LPC, CBIS

Like many states, North Carolina has experienced budget woes, reductions in rates for services, program shutdowns, and forced layoffs or furloughs for employees. It's clear we are not operating in an environment of "business as usual" these days. The good news is that reduced resources doesn't have to equal diminished opportunities or services. Often, the time to create new community initiatives is when changes in state and federal funding cause a reprioritization of resources.

The North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services allocates funding each year to Local Management Entities (LMEs) to address behavioral health needs of the designated counties under each LME. The LME, in collaboration with stakeholders, decides which services they will offer within the financial resources available for individuals without Medicaid or other insurance coverage. East Carolina Behavioral Health (ECBH) is the LME for Beaufort, Bertie, Craven, Gates, Hertford, Jones, Northampton, Pamlico, and Pitt counties in eastern North Carolina. East Carolina Behavioral Health works creatively with several different partners to improve the system and funds innovative options for consumers and families, working to achieve the best services in the most cost-efficient way.

Historically, North Carolina has favored funding for institutional, rather than community-based, services for people with intellectual or developmental disabilities. Institutional levels of care are not only more costly but also serve fewer people; these levels of care reduce the amount of funding available to serve people locally in their own communities. North Carolina could successfully fill funding gaps by closing the residential component of state-operated mental retardation centers and allocating dollars for more appropriate community-based services, as many other states have already successfully done.

There are waiting lists for developmental disability services, and ECBH is working hard to develop solutions to shortages and gaps in funding. Respite care, developmental therapy, adult day programs, and group living are some of the greatest needs that have been identified by families of disabled children and adults. ECBH developed resources and alternatives within available funding to meet these and other growing needs of communities. Unfortunately, due to limited financial resources, there is not enough for everyone to get what they want or, in some cases, need. For example, in the ECBH area, more than 4,200 people with intellectual disabilities and other developmental disabilities receive state-funded developmental disabilities services. As of November 2009, 328 people were waiting for funding for the Medicaid Community Alternatives Program for Mentally Retarded/Developmentally Disabled Individuals (CAP-MR/DD) program. ECBH works closely with consumers and their families to meet the needs of individuals who are waiting for a Medicaid waiver slot by offering funding to provide for the purchase of needed equipment and supplies that they might not otherwise be able to obtain without this funding. Annually, ECBH spends $128,000 in the purchase of individual equipment and supplies for people who are

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waiting for CAP-MR/DD waiver funding. This is in addition to other services that the person may receive while waiting for CAP funding. ECBH provides a parallel state-funded system of supports for consumers while they wait to receive the benefits of the more robustly-funded Medicaid waiver.

There are many people with intellectual and developmental disabilities (I/DD) who need support in a variety of residential settings. The annual cost to support a person to live in a group home setting is about $27,010 per year in the ECBH area, not including the cost of room and board. Increases in support for these programs are rare, and ECBH, like other LMEs, has many people who are on waiting lists for these types of services. Now more than ever before, people are seeking group home placements as parents age and families need a place for their adult family members with I/DD to live. Consumers and families also want options as each person is unique and needs a different level and type of support. ECBH currently supports 105 people living in group home settings, at a total aggregate cost of $2.9 million.

In an effort to extend the options for housing supports, ECBH recently purchased eight duplex apartments through The Arc of North Carolina. These duplexes will expand less restrictive housing options in the area for our clients and offer the opportunity for people to live in their own apartment with wraparound supports based on individual needs. The cost to support these 16 individuals to live in apartments is projected to be $10,555 per person per year.

ECBH has a strong focus on the rehabilitative needs of individuals who have survived a traumatic brain injury (TBI). However services currently offered do not adequately or appropriately address the unique needs of this population. Last year ECBH developed an alternative service definition to address the long-term residential and rehabilitative needs of TBI survivors. This service currently supports seven individuals living in residential settings. The cost to support these individuals to achieve their recovery potential is $333,620 per year, in aggregate. Support for the needs of this population cost an average of $51,100 per person per year. This cost supports requesting a waiver for this population as the needs are intensive and the potential for rehabilitation is great if the right type and amount of services are available within the first year after the initial trauma.

Flexible funding is not a new concept. Simply stated, this means that the person decides how to use the funding to get the services or support they need. The individual might create a specific service, take a class, buy equipment, make renovations to support independent living, or interview and hire a job coach who works directly for them to support employment. Flexible funding is one part of self-determination. Self-determination is a conceptual idea that allows people to choose the services and the providers they want and control other decisions because they themselves know best about what they need and how to make sure they get what they need. ECBH, now in its third year of collaboration with The Arc of North Carolina, supports eight individuals to be more self-determined. Each of these individuals has been able to design services that are unique to meet their needs.

Collaboration is the key to success for each of these individuals. Of course, the idea of collaboration isn't new; rather, it is the identity of the collaborators and the process of designing individualized services that takes this project beyond business as usual. In addition to family, friends, personal assistants, and agency personnel, new participants include church members, daycare operators, retailers, housing agencies, and a range of business, professional, and private citizens. It is this idea of rethinking and expanding our community connections that we believe is significant, especially in this era of shrinking resources. This is one of the most innovative projects ECBH has worked on since reform began; it is about new resources, new partnerships, new points of view, and new relationships.

Partnerships

Here are examples of the individualized solutions we have developed:

> Janey designed her own service to assist her in maintaining employment with a local retail store. Janey's needs did not fit within the context of currently defined services. Janey needed more than personal care and more than supported employment but needed both services at the same time. She had secured her own job but was unable to maintain it without supports. The project director at The Arc of North Carolina worked with Janey, her family, and Easter Seals UCP to develop Janey's service, which combines the elements of a personal care service with elements of supported employment and which revolves around Janey as a unique person. This service has supported Janey to maintain her employment for the past three years.
>
> Dana designed respite services to help support her to live in her own home while her father, her primary caregiver, works shift work. Dana and her father live in a rural area, and her father works out of state approximately two weeks each month. Dana does not have any other natural supports since the death of her mother, and she receives minimal services when her dad is in town. The Arc of North Carolina worked with Dana, her dad, and RHA Health Services to develop Dana's service to support her to remain in her home when her father had to go out of state. If this service had not been available, Dana may have needed to move to a group home or other higher level of care.
>
> Charles designed his own services to support his transition from a state institution back to his mother's home. Charles was living at Caswell, a state-operated developmental center. Charles's mother desperately

> wanted him to move home. In order for Charles to move home he required overnight awake staff within his home to maintain the safety of other family members until the transition was successful. The Arc of North Carolina and ECBH, through flexible funding, created an overnight awake service to ensure the safety of Charles and his family. Over time, this evolved as Charles became more stable at home, and the service has now become a PRN crisis response service available to the parent within 10 minutes.

While change is happening simultaneously throughout the behavioral health system in North Carolina, it is important to point out the successes that are occurring within the ECBH region. Working in partnership with consumers, families, and other stakeholders to create and design services which meet the needs of people is paramount. We know that when we give people the ability to design exactly the supports they need, we are saving financial resources and supporting the person to have the life they want. What is provided, who provides it, how and when it is provided, and where it is provided all impact a person's life.

As more people move out of institutions or decide to live more independently in communities, they will be looking for services that meet their unique individual needs. Options such as those being carried out in the East Carolina Behavioral Health region of the state offer exciting opportunities for success in supporting people to live in the community. Our belief is that by sharing our vision of possibility, sharing resources, and collaborating in new ways toward one common goal of improving quality of life for each person, we encourage people toward success. **NCMJ**

Improving Educational Outcomes and Post-School Success for Students with Disabilities

Berkeley Yorkery, MPP; David W. Test, PhD

In any given year, approximately 10,000 students with disabilities[a] start high school in North Carolina. Four years later, only half of these students graduate with a regular diploma (56.8% vs. 71.7% of all high school students).[1] Although North Carolina's graduation rate for students with disabilities has been improving (from 50.0% in 2007 to 56.8% in 2009), far too many students with disabilities are not leaving high school prepared for competitive work or postsecondary education. Surveys of students with disabilities who are no longer in school (due to graduating or dropping out) show that 27% were neither employed nor enrolled in school in the year after they left high school.[2] Students with intellectual disabilities were least likely to be engaged in work or school (47%).[2] Students with disabilities often face additional obstacles to success in school; however, we know that certain policies, programs, and services make them more likely to succeed both in school and in the transition to adulthood. North Carolina schools need to implement more evidence-based strategies to improve graduation rates and successful post-school outcomes for students with disabilities.

> **Students with disabilities often face additional obstacles to success in school; however, we know that certain policies, programs, and services make them more likely to succeed both in school and in the transition to adulthood.**

In-depth reviews of the experiences of students with disabilities have shown that many enter high school with weak academic skills and could benefit from comprehensive literacy and mathematics programs, but few high schools offer such services.[3] Under the Individuals with Disabilities Education Act (IDEA), all schools must provide a full continuum of special education services to students with disabilities, including the types of bridge courses mentioned above. The fact that many students with disabilities could benefit from bridge courses can be seen in their performance on end-of-course (EOC) tests for core academic areas (Algebra I, Biology, Civics and Economics, English I, and US History). Students with disabilities generally do not perform well on these EOCs, with less than 42% achieving a passing score (see Table 1).[b]

Adding to these challenges, North Carolina has recently revised its graduation requirements to make them more rigorous. In the past, all students had a choice of three courses of study (Career Prep, College Tech Prep, or College/University Prep) and some students with disabilities could also elect to participate in the Occupational Course of Study (OCS). The Occupational

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[a] Unless otherwise stated, "students with disabilities" in this article refers to all children with disabilities, regardless of the type of disability. The federal government recognizes 13 categories under which a child may qualify for special education including autism, deaf-blindness, developmental delay, emotional disturbance, hearing impairment, mental retardation, multiple disabilities, orthopedic impairment, other health impairment, specific learning disability, speech or language impairment, traumatic brain injury, and visual impairment.

[b] Passing EOCs for the five core academic areas is a graduation requirement for all non-exempted students.

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Table 1.
Only One in Three Students with Disabilities Perform at or Above Proficient on End-of-Course Tests in Core Academic Areas

	Algebra I (percent at or above proficient)	**Biology** (percent at or above proficient)	**Civics/ Economics** (percent at or above proficient)	**English I** (percent at or above proficient)	**US History** (percent at or above proficient)
Students without a disability	69.4% (n=125,799)	67.6% (n=86,431)	68.2% (n=96,117)	75.9% (n=100,417)	66.3% (n=82,929)
Students with a disability	33.2% (n=10,166)	37.6% (n=7,306)	37.4% (n=8,174)	35.4% (n=10,144)	41.8% (n=6,254)

Source: State Board of Education/Department of Public Instruction. *Report to the Joint Legislative Oversight Committee. North Carolina High Schools and Students with Disabilities: A Study of Educational Services and Outcomes.* Raleigh, NC: North Carolina Dept of Public Instruction and State Board of Education; 2009.

Course of Study is a transition-focused curriculum available only to students with disabilities and is designed for students with mild to moderate cognitive disabilities who need a modified general curriculum that focuses on post-school employment and independent living. Federal law requires that no more than 2% of students take alternate assessments (which students in the OCS do), which limits the number of students who can elect to follow the OCS.[c] The new guidelines, effective for all incoming 9th graders for the 2009-2010 school year, have only two courses of study for students with disabilities: the Future Ready Course of Study, which is very closely aligned with the previous College/University Prep course of study, and the OCS. Although the OCS is still available to some students with disabilities, the requirements for the OCS have been increased (for example, students in the OCS will have to pass algebra to graduate). These changes will likely make it more difficult for students with disabilities to graduate.

Schools play a critical role in helping all children acquire the skills and knowledge needed to be successful as adults. This is particularly true for individuals with intellectual or developmental disabilities (I/DD) who may face additional challenges as they transition into adulthood. According to IDEA, all students with disabilities are required to have an Individualized Education Program (IEP) to help ensure they receive the individualized attention and supports they need to succeed in school. Even though students with disabilities have IEPs, many still lack the supports necessary to successfully complete high school and transition into independent living, employment, or post-secondary education.

As part of their IEP, all students with disabilities are supposed to have postsecondary goals and a transition plan in place that includes coordinated transition services which will reasonably enable the students to meet their goals. In 2007, 85.8% of students with disabilities ages 16 and older had postsecondary goals and a transition plan as part of their IEP. Although this is an improvement (only 60% had them in 2005), it is clear that many students with disabilities in North Carolina are not receiving the guidance and support mandated by IDEA. Of those IEPs with postsecondary goals and a transition plan, 50% did not involve agencies outside the school.[2] Including agencies outside the school is critical to ensuring the successful integration of students with disabilities into their communities. In particular, students with I/DD need to establish linkages to postsecondary schools, vocational rehabilitation, Local Management Entities (LMEs), and other agencies and organizations that provide support early on to ensure they become active participants in the community when they leave high school.

In order to ensure full implementation of IDEA and to help states build capacity and support for children with disabilities, the National Secondary Transition Technical Assistance Center[a] (NSTTAC), under the US Department of Education, Office of Special Education Programs, identifies evidence-based and promising practices for transitions. NSTTAC research has identified a number of in-school predictors of post-school success in employment, education, and independent living (see Table 2, page 544) and matches them to evidence-based practices that can be implemented in high schools.

NSTTAC has matched each in-school predictor to evidence-based practices that support that particular predictor. For example, occupational courses improve employment and independent living outcomes. Occupational courses may teach evidence-based practices including

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c. Lee F. Consultant, Mental Disabilities, Secondary Education and Transition Services, Exceptional Children Division, North Carolina Department of Public Instruction. Oral communication. February 11, 2009. Written (email) communication. February 19, 2009.

d. The National Secondary Transition Technical Assistance Center, based at the University of North Carolina at Charlotte, is federally funded to identify research-based practices in transition, disseminate these practices, and assist states in their adoption.

Table 2.
In-School Predictors of Post-School Success

	Employment	Education	Independent Living
Academic/general education		✓	
Career awareness	✓	✓	
Community experiences			✓
Exit exam requirements/high school diploma status		✓	
Interagency collaboration		✓	
Occupational courses	✓		✓
Paid work experience	✓		✓
Parental involvement		✓	✓
School integration	✓	✓	✓
Self-advocacy/self-determination		✓	✓
Self-care/independent living skills	✓		✓
Social skills	✓	✓	✓
Student support		✓	✓
Transition program	✓	✓	✓
Vocational education	✓		
Work study	✓		

Source: Test DW, Mazzotti V, Mustian A, White J, Fowler C. Evidence-based secondary transition practices and predictors. Presented to: The North Carolina Institute of Medicine Task Force on Transitions for People with Developmental Disabilities; November 19, 2008; Morrisville, NC.
Note: For the current list of predictors, see: http://www.nsttac.org/ebp/PredictorFiles/PredictorsByOutcomeTable.pdf

functional reading and math, banking skills, purchasing skills, and life skills. For many evidence-based practices that are identified, the NSTTAC provides lesson plans to help teachers implement the practices. These lesson plans are free and available for teachers online. Although many of these evidence-based practices could be incorporated into courses for students with disabilities for little cost, the increasing focus on academic coursework over the past decade has left little time for courses teaching life and occupational skills.

In order to best serve children and young adults with disabilities in the least restrictive settings and to integrate them into communities as they become adults, schools must help students acquire the skills and knowledge needed to succeed in postsecondary education, the workforce, and independent living. North Carolina schools could be doing much more to meet the needs of students with disabilities. The NSTTAC has identified a number of evidence-based practices that schools can integrate into coursework for students with disabilities and can provide the technical assistance schools need to implement these practices. By implementing evidence-based practices, North Carolina schools would considerably improve the chances that our students with disabilities will be successful, not just in school, but also in life. **NCMJ**

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College: An Option for People with Intellectual or Developmental Disabilities

Joan Johnson; Terri Shelton, PhD

In August of every year, a familiar scene unfolds in communities across the nation. The exodus from home communities to college campuses has begun! This is an exciting, but anxiety-producing time for many young adults. It is a time of letting go for their parents.

Visualize cars loaded down with the trappings for a college dorm, the student seeing their college housing complexes, parents carrying all those boxes in, and the newly minted freshmen surveying the landscape nervously but with happy anticipation. A student sees possibilities at every turn, but the parent is conflicted about the "launch." Sons and daughters convince moms and dads that it is time to leave. It is a benchmark event in most young adults' lives as record numbers of graduates continue their education after high school.

A New Beginning

Now, take in this scene at the University of North Carolina at Greensboro (UNCG). The influx of students to UNCG this past August broke enrollment records; however, there is a unique feature that UNCG boasts in their services to students that few observers would be able to discern. Among the new freshmen are students with intellectual disabilities. In fact, there are returning students with intellectual disabilities who have flourished on the UNCG campus for the previous two years. The beauty of this scene is the inclusion of students with intellectual disabilities with their peers in a very ordinary life phase for young adults. Such is the partnership of UNCG and Beyond Academics, an extraordinary collaboration of postsecondary education for students with intellectual disabilities in North Carolina.

> *Beyond Academics at UNCG is North Carolina's first progressive and inclusive higher education site in a university community for young adults with intellectual disabilities.*

Beyond Academics is a private, nonprofit human services agency dedicated to supporting and instructing young adults with intellectual disabilities who hope to advance their education after high school. Life coaching and support are provided on campus, in collegiate housing complexes, and in the community in partnership with UNCG. Beyond Academics at UNCG is North Carolina's first progressive and inclusive higher education site in a university community for young adults with intellectual disabilities.

The planning initiative started in 2004 with a foundation of community grassroots activism, represented by students with intellectual disabilities, parents, and other community stakeholders in Forsyth County. The stakeholders did not need gap analysis data to know there was a problem. They knew, firsthand, the dearth of inclusive community capacity that supports growth for young adults with intellectual disabilities. Committee members learned of a few postsecondary education programs in collegiate settings in other states through some national contacts. There was an urgency to get started with the development of a program in North Carolina.

Beyond Academics was an "out of the box" idea, initially difficult to sell as a viable long-term option. However the planning committee persisted, with one community provider agency stepping forward to offer incubation of this novel concept in his own business. Charles Hines and Son, Inc. of Winston-Salem provided the seed funding for start-up of the concept. As a parent of a son with autism, Andy Hines, president and CEO of Hines and Son, Inc. could clearly envision the promise of such an option for young adults leaving high school. The first order of business was to engage a willing college as a partner.

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UNC Greensboro has a reputation for embracing campus diversity and is willing to stretch for innovation. Thus, when approached with the idea, UNCG leadership asked the necessary and hard questions regarding Beyond Academics, and then they stepped out on a limb of uncharted territory in North Carolina education.

An equally important task was to convince state agencies that a postsecondary education pilot program was a good risk. The concept was articulated to the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, the North Carolina Division of Medical Assistance, and the North Carolina Council on Developmental Disabilities as a promising practice for young adults with intellectual/developmental disabilities. These state partners shared the vision and moved ahead with technical and other resources to start the program with eight students in August 2007.

Being a college freshman has taken on a new definition in North Carolina with the advent of Beyond Academics. What is a presumed practice for many young adults is now an opportunity for young adults with intellectual disabilities. Most families never imagined that this day would come for their sons and daughters with intellectual disabilities. Indeed this opportunity, as stated so eloquently by a parent of a charter Beyond Academics student, is a linchpin in assuring social justice and economic self-sufficiency for individuals with intellectual disabilities. Education and training create a level playing field for our country's citizens, with a significant impact on opportunity and quality of life. Access to postsecondary education is a necessity for *all* citizens.

The Need Validated

The gap in viable postsecondary education options is a "hot button" topic across the nation. The North Carolina Institute of Medicine has conducted a comprehensive study on transitions for people with developmental disabilities and intellectual disabilities. Based on 2007 North Carolina Department of Public Instruction data, at least 50% of North Carolina students with intellectual disabilities, in the year following the completion of secondary education, are not connected with employment or postsecondary education.[1] This is not unique to North Carolina. Unfortunately, across the nation scores of young adults with intellectual disabilities are reaching a veritable dead end after high school.

Much feedback from prominent advocacy groups such as the National Down Syndrome Support Network, the National Down Syndrome Congress, and The Arc of the United States about a growing crisis has alerted policymakers. The US Administration on Developmental Disabilities, in partnership with the US Administration for Children and Families and the US Department of Health and Human Services, has funded a collaborative national project focused on development of postsecondary education options for students with intellectual disabilities. "Think College" is a consortium led by the University of Massachusetts at Boston, and it has developed a network for existing and emerging postsecondary education programs. The purpose is to provide information to students, families, and professionals in the service and education arena about postsecondary education sites. Of equal importance is the project's promotion of research, program development, and evaluation.

A survey indicates that there are more than 150 postsecondary education programs for students with intellectual disabilities in the nation, but there has been no coordination of research, model development, and information sharing for replication.[2] The establishment of this consortium will bring a systematic approach to the development of postsecondary education options with an eye to quality outcomes.

"Think College" recently provided data analyses of outcomes for young adults with intellectual disabilities who had left high school. The data derived from the national vocational rehabilitation database (RSA 911) shows that participation in postsecondary education has a significant positive impact on getting a job, keeping it, and increasing earning power. Postsecondary education options for individuals with intellectual disabilities are not widely available and accessed. The survey examining outcomes for those who did not participate in postsecondary education services showed only 32% of young adults sustaining employment with average earnings at 62% of what young adults who had participated in a postsecondary education program earned.[3] This national trend could be averted in North Carolina by having adequate postsecondary education options.

The Model and the Evaluation

Beyond Academics at UNCG is based on a typical undergraduate experience in the college setting. Entering its third year, the program serves 25 students in the freshmen, sophomore, and junior classes. The senior year of the program is now under construction. The course of study covers 10 competencies that advance in complexity with each year of enrollment. All coursework is tested and graded with expectations for a certain level of mastery to attain credit hours. Competencies are taught through inclusive classroom and Beyond Academics-dedicated classroom experiences. Core competencies include personal well-being, nutrition management, relationships, advocacy, household management, financial literacy, transportation, social responsibility, career development, and community inclusion and social networks.

The classroom experience makes up one-third of the equation for competency standards in each of these topical areas. The remaining two-thirds of academic time offers opportunities for students to apply their skills. The unique feature of Beyond Academics is the emphasis on an inclusive lifestyle with other students. The student housing complexes, the internship and employment sites, and the community social networks are the venues for Beyond Academics students to practice what they have learned. The focus on connections with other college students provides a rich environment for service learning. The benefit of the connections and relationships for the Beyond Academics students and the UNCG students is reciprocal.

UNCG departmental involvement is growing. The Department of Kinesiology, through its Therapeutic Recreation Program, was the first university partner with Beyond Academics. There are numerous opportunities through this department for inclusive classes and projects undertaken in the community. More recently, the Department of Specialized Education Services, the Human Development and Family Studies Department, and the Communication Sciences and Disorders Department have emerged as partners in shared classroom and other related activities. The interest continues to grow on campus and includes opportunities for the Beyond Academics students to audit select college classes of interest. Conversely, Beyond Academics' focus on mastering independent living has captured the attention of some UNCG students who indicate the usefulness of that information in their own growth.

The North Carolina Council on Developmental Disabilities understood the need for a studied approach to developing postsecondary education models. Two years ago the Council awarded a research and model development grant to the Center for Youth, Family, and Community Partnerships at UNCG. The Center gathers and analyzes important data about the Beyond Academics operation, using results for model development with a goal of site replication in North Carolina. Evaluation protocol includes goal attainment scaling, anecdotal information related to student progress in class attendance, class auditing, recreational activities and volunteerism, and service learning. Other areas under review are social connectedness, adaptive functioning, student satisfaction, family satisfaction and perceptions, UNCG student outcomes, and economic cost/benefit.

Student outcomes are promising and will determine how the model develops. Students are living on their own with the majority needing fewer supports than when they started, and they are engaging in a life of social connections not previously experienced. Students are learning to manage their own financial affairs. Through their jobs, they are learning the ethic of work. They are asserting their voices in challenging real and perceived injustices that might occur because of their disability. Finally, students are assuming other meaningful roles that will help them achieve the life they imagined. They are hopeful about their futures.

Taking up the Challenge

Every year of operation produces more learning and improvements for the program. One could describe this experience as "the glory and the agony." The glory is the promise that young adults with intellectual disabilities will achieve a self-determined life; the agony is the narrow availability of the service throughout the state.

Systemic challenges that have to do with funding, policy, and philosophy of this kind of program will need to be addressed. The gains for students that have been made because of the Individuals with Disabilities Education Act (IDEA) will be for naught if we do not summon the collective resources to go the next step for continued growth and learning. A system predicated on caretaking versus self-reliance will cost more than our investment in empowerment of people.

Is Beyond Academics for every young adult with an intellectual disability? No, but neither is college the preference of every young adult who graduates from high school. However, the difference for individuals with intellectual disabilities is the availability of the opportunity to attend and succeed in community college or university-based programs, if he or she chooses to do so

Beyond Academics is but one vehicle for postsecondary education and training for students with intellectual disabilities. Community college is another rich resource that has incredible promise and ready access. Just as universities and community colleges work together for countless students in North Carolina, the same needs to happen for students with intellectual disabilities. North Carolina is at the crossroads. We must commit to the direction that brings lasting results and a meaningful life to individuals with intellectual disabilities. More opportunities for lifelong learning are the conduit for these outcomes. **NCMJ**

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The Need for Employment Supports for Persons with Intellectual and Developmental Disabilities in North Carolina

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Michael Maybee, QDDP; Jim H. Swain, MAEd, MS

Supported Employment services began in North Carolina in the mid 1980s as a result of a systems change grant from the US Department of Education's Office of Special Education and Rehabilitation Services (OSERS). At that time, an agreement was made between the North Carolina Division of Vocational Rehabilitation (NCDVR) and the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (DMHDDSAS) that stipulated that NCDVR would fund what is commonly termed within the field the "front end" of the service model—job development, job placement, training, and stabilization. DMHDDSAS would, in turn, fund the extended services after a successful job placement that would assure continued employment success. These services are typically referred to as long-term support (LTS). Over the years, North Carolina has been a leader in supported employment services and ranked third in the nation for meeting federal requirements for successful closures in 2006.[1] But at the same time, North Carolina has struggled to create and maintain a consistent funding stream for the necessary and required extended LTS services that are critical for helping individuals with intellectual and developmental disabilities (I/DD) maintain employment successes.

Supported employment is...a work model that assumes that all individuals, regardless of the nature or extent of their disabilities, should have the opportunity and support to work in the community.

Supported Employment Defined

Supported employment is, by definition, a work model that assumes that all individuals, regardless of the nature or extent of their disabilities, should have the opportunity and support to work in the community. No prerequisite skills are required for community job success. The model stipulates that individuals do not necessarily have to be "work ready," but rather the goal is to locate and/or modify meaningful jobs in the community and provide training and supports at the job site.[2] The 1986 reauthorization of the Rehabilitation Act of 1973 (PL 99-506) defines the term "supported employment" within the federal guidelines as:

> *...competitive work in integrated settings (A) for individuals with severe handicaps for whom competitive employment has not traditionally occurred, or (B) for individuals for whom competitive employment has been interrupted or intermittent as a result of a severe disability, and who, because of their handicap, need ongoing support services to perform such work.*

The Stages of Supported Employment

Within the supported employment service approach, the employment specialist, once referred to as the job coach, is responsible for assisting the consumer in locating a job and preparing for the interview, and then providing on-the-job training to the degree necessary to assure a successful employment outcome. Once the employment specialist determines that both the consumer and the employer are satisfied with the job placement, the goal of transitioning into the extended phase of supported employment begins. This phase is commonly referred to as extended services, or long-term support. For persons with I/DD this is more often than not the most critical phase for job retention. It is at this stage that individuals tend to lose their jobs not because of an inability to perform the tasks, but instead due to changes in work routines or supervisors or because

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of difficult interactions with coworkers. The difficulty may also be personal, such as financial hardship. Despite the importance of LTS, this area of supported employment has received little attention.[3]

In North Carolina, as in most other states, the majority of supported employment services are funded first by NCDVR, which pays for job assessment, job development, and the initial job training that occurs on the job site. NCDVR does not hire and/or manage employment specialists directly, but rather contracts with over 100 nationally accredited community rehabilitation programs (CRPs) to provide supported employment services in North Carolina. NCDVR and its partner agencies provide services that support people with I/DD in their efforts to obtain meaningful work, with the goal of supporting people in competitive employment. Through its partnerships with these community rehabilitation programs, NCDVR is able to provide customized employment assessments and assist individuals with the most significant disabling conditions find competitive employment in the workforce.

The Elements of Long-Term Support Services

Once an individual is able to complete his or her job under the conditions of the work environment, as previously mentioned, he or she moves into the LTS phase of supported employment. The intended goal of LTS is to assist the worker in the identification and provision of supports and extended services necessary to maintain and enhance the person's position as a member of the workforce. The employment specialist may:

- Monitor work performance including work quality and work rate.
- Facilitate job changes and career advancement.
- Provide crisis intervention.
- Monitor socialization and overall integration into the work culture.
- Support training for the employer and/or coworkers.
- Retrain previously learned skills.
- Train the worker on new job skills added to the position.
- Assess the worker's job satisfaction.
- Assist the worker with changes in benefits resultant from wages earned.
- Assess the supervisor's/employer's satisfaction with the worker.[4]

Approximately 80% of the funding received by DVR is federal; thus, federal regulations determine which vocational rehabilitation services can be funded. Federal regulations clearly state that the funds received for supported employment services cannot be provided longer than 18 months unless under special circumstances. Furthermore, such funds cannot be used to support "extended services" after the individual has made the transition from state vocational rehabilitation agency support.[5]

As previously mentioned, DMHDDSAS has had the role of funding long-term support services since the inception of supported employment within North Carolina. Typically these services have been funded through a variety of sources, including but not limited to the Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities (CAP-MR/DD) waiver and ADVP state funds. Funds are administered by Local Management Entities (LMEs) and their provider network. LMEs are county-led governing agencies charged with the oversight of human services provided at the local community level. They administer funds allocated from DMHDDSAS and subsequently contract for service provision through private providers. Providers of supported employment services in North Carolina have long complained of inconsistency in funding LTS, and, in some cases, no funding at all.[6]

Prior to January 2003, the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services did not have dedicated funding for long-term support services. Funding streams were mixed within supported employment service definitions and often created confusion and difficulty in tracking actual expenditures of long-term support services. Following the creation of a dedicated service definition for LTS (DMHDDSAS Long-Term Vocational Support Services—Extended Services), grassroots efforts from provider organizations and consumers were successful in lobbying the North Carolina General Assembly to obtain an appropriation toward this service in the amount of $1.5 million during the 2005 legislative session. In the 2006 session, another $2.5 million was obtained for a total of $4 million dedicated to LTS for those individuals meeting eligibility criteria within the mental health system. Since that time, distribution of these funds to providers offering long-term support services has been an ongoing concern amongst all stakeholders involved within the supported employment arena. As noted in the May 2009 NCIOM Task Force Report, *Successful Transitions for People with Developmental Disabilities,* "while DMHDDSAS had $4 million appropriated for this purpose, the LMEs only spent $2 million in SFY 2008 for 'long-term vocational supports.'"[7] With the tremendous need for long-term support services and the scrambling for funds that has occurred over the years, North Carolina cannot afford to have funds appropriated for this purpose that are not fully maximized.

North Carolina has been a national leader in the supported employment arena, with the number of job placements averaging approximately 1,000 persons annually. For North Carolina to continue to be a leader in the provision and advancement of employment options for individuals with I/DD, a solution to the lack of and/or inconsistency of long-term support funding must be found. The joint supported employment services of vocational training and long-term supports suffer due to a lack of seamless service delivery. Nationally and in North Carolina, a significant barrier to the

Life Plan Trust:
A Resource for Future Planning

Susan Hartley

Life Plan Trust, a private nonprofit corporation, serves clients with developmental disabilities and/or mental illnesses. There are four regional offices, and services are provided statewide by a staff of six. Life Plan Trust was founded and is cosponsored by The Arc of North Carolina, the National Alliance on Mental Illness (NAMI) North Carolina, Easter Seals UCP North Carolina, and the Autism Society of North Carolina.

Parents of children with disabilities find it difficult to think about a time when they will not be involved in their son or daughter's life due to their own illness or death. It is extremely important for parents to address this issue early on. If you die without a will, assets you do not hold jointly with your spouse or someone else will go to your estate, and North Carolina has a formula for how these assets are to be divided. The majority of the assets will go to children, even if a child has a disability. If the child receives Medicaid, Community Alternatives Program (CAP) services, special assistance, or Supplemental Security Income (SSI), inheriting money may cause these benefits to stop if the amount of countable assets exceeds $2,000. Regular unearned income, such as annuity payments, can also affect SSI and Medicaid benefits, as well as housing subsidies. Planning ahead for the best use of financial assets is a much better option for surviving family members than an unexpected inheritance; some individuals with disabilities may not be able to handle a lump sum of money or may be exploited by others.

Families often express concerns about the difficulty of accessing information on government benefit programs and eligibility requirements—finding information takes numerous phone calls to several agencies and often results in different answers. Life Plan Trust provides information on benefit eligibility and how different types of estate planning can impact eligibility for programs such as SSI and Medicaid. Individuals receiving Medicaid and SSI are generally not allowed more than $2,000 in assets, but there are some types of trusts that are allowable resources. Typically, these trusts can be used for supplemental needs (not food or shelter) in order to be excluded as a resource.

Another concern that parents express is the lack of available choices to serve as trustee. Larger banks require a minimum of $500,000 in an individual trust account. While bank trust officers are very good at managing money, they may not be knowledgeable about the needs of persons with disabilities or what support services may be available. Parents may be reluctant to ask family members to take on this responsibility. Enrolling in Life Plan Trust brings peace of mind to parents, knowing that support systems will be in place for family members during a parent's illness or after his or her death. Each beneficiary who enrolls has an individualized Careplan that addresses the person's strengths and needs, defines the role of Life Plan Trust in the beneficiary's life, and sets goals and objectives for trust funds. Life Plan Trust services are part of a team approach, working with residential and vocational providers to use the available funds wisely. While Life Plan Trust cannot provide residential supervision for the individual with a disability, Careplan services can add significantly to the individual's quality of life by providing oversight, advocacy, regular visits, and contacts, ensuring that other family members are kept informed about the beneficiary and making sure there are birthday and other holiday-related gifts. Life Plan Trust accepts a variety of trust amounts; the majority of currently funded trusts are less than $40,000. Life Plan Trust can only be named as Trustee if an advance enrollment is completed. However, it is not necessary to fund the trust at enrollment; it can be funded when a parent passes away from the proceeds of life insurance policies or other estate assets.

While many trusts are funded from parents' assets, trusts can also be funded by the individual with a disability by a back payment from Social Security, a personal injury settlement, or unexpected inheritance. Establishing a Pooled Trust may be an option to help restore essential benefits like Medicaid, and this is considered an allowable transfer of resources under Medicaid regulations. A Pooled Trust is a way for money that is in the name of the person (under 65 years old) with a disability not to jeopardize benefits. It is an allowable transfer under Medicaid and SSI regulations to transfer these funds to a Pooled Trust, which has a payback to Medicaid at the end of the person's life.

In our 19th year of operation, Life Plan Trust has over $6.5 million in client trust funds under management (in conjunction with Wachovia Charitable Services as our financial manager). We currently oversee 104 funded trusts and an additional 175 trusts that will be funded in the future (at the death of the parents). Life Plan Trust only serves trust beneficiaries with developmental disabilities or mental illnesses, so our staff is very knowledgeable about government benefit eligibility rules and how trust funds can be utilized without jeopardizing other essential benefits, such as Medicaid. To receive a free information packet containing information about effective future planning and government benefit eligibility, please contact us at 1.888.301.0799 or email lifeplan1 (at) earthlink.net. For more information about Life Plan Trust, please visit http://www.arcnc.org/services/life_plan_trust/.

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seamless delivery of supported employment has long been its multiple funding sources and a service delivery model which is responsible to separate divisions of government.[8] To further the complexity of this system within North Carolina is the involvement of the LMEs, which all have their own way of conducting business within their catchment areas around the state. This funding system naturally evolved in response to the restriction that federal vocational rehabilitation funds may not be expended for extended services beyond the successful supported employment closure. Many states around the country complain of similar situations whereby long-term support funding is hampered in reaching providers of such services. At least one state has used an alternative means of long-term support funding where the state vocational rehabilitation program administers state funds and utilizes their vendor network.[9] Whether the state has seen greater success utilizing this method has not been reviewed for this commentary.

The funding system that would work best for North Carolina, one that enhances the delivery and subsequent funding for long-term support services, has yet to be developed much less implemented. It is apparent that the system North Carolina has utilized for years has struggled to provide consistent funding to meet the needs of the supported employment program. For North Carolina to truly embrace an "Employment First" philosophy as proposed within the DMHDDSAS strategic plan for 2007–2010 and to continue to add 1,000 plus new individuals to supported employment jobs each year, there must be a statewide, seamless, designated, and protected funding stream for the long-term support services that are essential to the success of supported employment. There must be future efforts to study best practices around the country in the effective administration of long-term support funding and incorporate those practices in an effort to promote a better system within North Carolina. There is too much to lose in not pursuing this path. Individuals with I/DD deserve the opportunity to not only secure satisfying jobs, but also to have those supports necessary to maintain and grow within those jobs, thereby enhancing their lives through work. As the saying goes, there is dignity in work. **NCMJ**

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Bridges to Community:
The Challenges and Necessity of Building a Quality Direct Support Workforce

Holly Riddle, JD, MEd

“One of the challenges facing the US in the 21st century will be to ensure that individuals of all ages receive, throughout their lives, the health and social support services they need to live with dignity as fully included members of our society. For the estimated 4.3 million Americans of all ages with intellectual disabilities and/or developmental disabilities (ID/DD) living in residential settings, their own homes, or with members of their families, ensuring access to and quality of direct support professionals (DSPs) is key to realizing national goals established in the Americans with Disabilities Act, the Developmental Disabilities Assistance and Bill of Rights Act, and other statements of national purpose with regard to the full citizenship and inclusion of individuals with ID/DD.”[1]

The quality of direct support provided to people with intellectual and other developmental disabilities (I/DD) lies at the heart of their satisfaction with the services paid for by the state of North Carolina. Moreover, North Carolina’s commitment to its frontline human services workforce in the field of intellectual and developmental disabilities—as well as in mental health, addictive diseases, and aging—is essential to the state’s efforts to build a person- and family-centered community system that is cost-effective and achieves outcomes associated with quality of life, such as good health, community integration, and participation in activities of one’s choice.[2] Individuals with I/DD and their families know that the quality of the direct support workforce can be the difference between a satisfying life or a life fraught with emotional distress or even harm. To begin to grasp this statement if you are among those who are “temporarily able-bodied,” imagine depending each day, wholly or partially, on one or more individuals who are paid to assist you in participating fully in those ordinary activities that we call living. Imagine, if you will, being left in the tub while the water turns cold, unable to warm it up; trying to reach a wallet that’s been placed in the wrong pocket—or isn’t there at all; or having someone change the channel on your TV in the middle of an Atlantic Coast Conference basketball game and ignoring your exasperated protest. Imagine further that when the service provider who employs the worker finally sends someone who gets your hair just right; who has the professional demeanor appropriate to accompany you to your workplace; and who employs the skills to transfer you safely from your power chair to bed, the worker leaves because she’s allergic to the cat she didn’t know you had, or because she was not told in advance that she had to do *that*, or because she’s found a better paying job. This is the dilemma of all too many people with I/DD and their families—especially in a budgetary crisis, when services are already limited or nonexistent. At a systems level, these challenges are the tip of an iceberg that could undermine the ability of the state to deliver on its renewed promise of high-quality I/DD services and supports.

Individuals with I/DD and their families know that the quality of the direct support workforce can be the difference between a satisfying life or a life fraught with emotional distress or even harm.

North Carolina is facing a workforce crisis that compromises all human services. The aging of a large part of the population—the “baby boomers”—means that there are more people who need human services of all types and less people to provide them. Human services, already hard hit by a budget crisis expected to last several more years, must compete with other sectors of the economy for a shrinking pool of available workers. In this climate, people with I/DD are more significantly impacted than

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other groups. They require more support of more varied types, with more activities of daily living, over a longer period of time than others with disabilities.[2] Many of these services are provided by frontline workers known as direct support professionals (DSPs). DSPs work in diverse settings, including people's homes, group homes, sheltered workshops, supported employment programs, day activity centers, public developmental centers, nursing homes, and, increasingly, just about anywhere out in the community that we all go. DSPs work with people across the lifespan, from birth to old age, in different sectors of the human service delivery system, sometimes with several people in the same week. DSPs often know the individual better than other paid staff and are responsible for activities such as ensuring that support plans and interventions are correctly and competently carried out and the intended outcomes are achieved. A crisis in this sector of the workforce is one that people with I/DD and their families experience personally, daily, and profoundly.

"Direct support professional" is a relatively new occupational title. It unifies for the first time a workforce that has previously gone by many names (e.g., direct support workers, direct care workers, personal care assistants, home health aides, and nursing aides).[a] It is a workforce for which demand is growing exponentially in North Carolina and across the nation. From 2004 to 2014, the North Carolina Employment Security Commission projects that DSP occupations will be among the top 10 fastest growing occupations in the state. Jobs for home health aides are expected to increase by 48.3% over this period; nursing aides, orderlies, and attendants by 27.8%; and personal and home care aides by 49.5%. Over the next decade, these occupational titles alone are expected to create a total of almost 40,000 job openings.[3] Changing demographics, however, are already pressuring the state to meet workforce demands. The number of baby boomers over age 65, including people with I/DD, is rapidly outpacing the much smaller cohort of workers available to support them, and the turnover among existing DSPs is high.[b] Waiting lists for I/DD services are growing, with estimates of an increased demand for services at 37%. At current turnover rates, data indicate that by 2020 approximately 18,780 new DSPs will be required to support those receiving services.[4] Attracting and—just as importantly—retaining an adequate supply of workers to this newly-named profession will require large-scale marketing initiatives and clear, coordinated, and cohesive policy change.

Such policy change flows in large part from the emerging role of direct support professionals in North Carolina's emerging community-based, regionally-managed mental health, developmental disabilities, and addictive diseases system. The state is undergoing a transformation from an institutional care model to a community-based human services model. The new model places primacy on person- and family-centered services and support, provided in one's own home and community. The shift in orientation from centralized, congregate care towards personalized services and supports calls for new, more robust roles for DSPs, in addition to their role in medication support and health and wellness activities. DSPs are "bridge builders" who facilitate connections to the people, resources, and experiences necessary for those with I/DD to live full and safe lives. One of the implications of this role change is reflected in the addition of the word "professional" to an occupation historically viewed as paraprofessional. Direct support staff once worked almost exclusively in congregate settings where their performance could be readily observed by supervisors and managers. Increasingly, however, people with I/DD grow up, go to school, live, learn, work, play, and retire in communities and move through the same settings as do people not affected by disability. This means that DSPs working in the community may not have daily, face-to-face contact with supervisors. The increased responsibilities and exercise of independent judgment associated with the delivery of services and supports in the community settings that all citizens share make it essential that DSPs indeed be professionals. Like any professional, they must demonstrate the competencies and the knowledge, skills, and attitudes required to be effective.

The North Carolina Council on Developmental Disabilities,[c] the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (DMHDDSAS), and the North Carolina Providers Council are collaboratively advancing a welcome change with regard to the training

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[a] "Direct support professional" is the term adopted by the professional association, the National Alliance of Direct Support Professionals, for this sector of community human services (see http://www.nadsp.org for more information). While its origins are in the field of I/DD, the term is increasingly being used in other service sectors.

[b] A review of 13 state and two national studies between 2000 and 2007 suggests that, dependent upon setting, job turnover rates in the field of intellectual/developmental disabilities range from 42% to 69%. (Hewitt A, Larson S, Edelstein S, et al. *A Synthesis of Direct Service Workforce Demographics and Challenges Across Intellectual/Developmental Disabilities, Aging, Physical Disabilities, and Behavioral Health.* Washington, DC: National Direct Service Workforce Resource Center; 2008.)

[c] The North Carolina Council on Developmental Disabilities (NCCDD) is an independent agency established under the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 106-402). It is mandated to conduct systems change, advocacy, and capacity building on behalf of all North Carolinians with intellectual and other developmental disabilities. The NCCDD is comprised of people with I/DD, family members, policymakers, legislators, and other representatives of the state's service delivery system, including the state's Protection and Advocacy System (Disability Rights NC) and its University Center on Excellence in Developmental Disabilities (Center for Development and Learning, UNC Chapel Hill). See http://www.nccdd.org for more information.

of DSPs.[d] We are re-examining traditional, hours-based training on rules and regulations in favor of curricula built around clearly articulated standards, values, competencies, and skills. Such training could someday lead to a portable, nationally-recognized certificate or credentialing system for North Carolina's DSPs. While such developments are perhaps long overdue, it has only been in the last 100 years that nursing and social work could be deemed professions, as evidenced by the adoption of the first standardized curriculum for the former in 1917 and for the latter in 1939.[5]

Enhancing the competence, stability, and job satisfaction of DSPs will go a long way towards addressing the challenges identified by the North Carolina Council on Developmental Disabilities in its *Direct Support Professional Work Group Report*[4] (2007), developed in collaboration with the DMHDDSAS, for the North Carolina Commission on Mental Health, Developmental Disabilities, and Substance Abuse. These challenges are:

- Retaining existing direct support professionals.
- Meeting a significant increase in the demand for direct support professionals in the face of employee shortages.
- Addressing a high turnover rate that compromises services and supports for consumers, adds to provider costs, and increases the demand for replacement workers.
- Addressing direct support professionals' low wages and extremely limited access to health care insurance and other benefits.[e]
- Meeting the need for comprehensive training of direct support professionals to ensure knowledge, skills, and competence in provision of services to people with disabilities and their families.

Recommendations of the *Direct Support Professional Work Group Report*[4] include the following activities:

1. Create a permanent structure and state-wide advisory capacity.
2. Create a certificate or credentialing program for DSPs.
3. Increase the wages of DSPs.
4. Create a marketing and public awareness campaign.
5. Provide systematic training, technical assistance, and incentives to all community providers in North Carolina on effective recruitment retention and training practices.
6. Provide system-wide training to supervisors and managers on effective supervision.
7. Provide opportunities to empower DSPs.
8. Create new service options for consumer-directed services for individuals with disabilities and, as appropriate, their families.
9. Provide access to affordable health insurance benefits for DSPs.
10. Create recruitment/selection tools to assist providers in reducing early turnover.

Along with thousands of others across the nation, we are witnessing the birth of a new profession, one that has more potential for offering its practitioners a living wage and a viable career path. Just as importantly, North Carolina's next generation of direct support professionals will enhance the opportunities for people with I/DD to realize their dreams and enjoy the daily liberties and human rights that others take for granted. **NCMJ**

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[d] The North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services is undertaking a review of current policy and practice with regards to staff competencies. The North Carolina Council on Developmental Disabilities has funded a grant to the North Carolina Council of Community Support Providers to demonstrate the College of Direct Supports (CDS). The CDS is an interactive, online, competency- and values-based curriculum for direct support professionals. The CDS is now being used in 23 states and by more than 300 agencies. Approximately 40,000 learners across the United States are enrolled in the curriculum. See http://info.collegeofdirectsupport.com for more information.

[e] Direct support workers working in the private sector for persons with I/DD are paid near poverty level wages, averaging, according to one study, from $7.30/hour to $15.18/hour with a mean of $8.68/hour. Many do not have health insurance or depend on Medicaid. (Larson SA, Hewitt AS, Knobloch B. Recruitment, retention and training challenges in community human services. In Larson SA, Hewitt AS, eds. *Staff Recruitment, Retention and Training Strategies for Community Human Services Organization.* Baltimore, MD: Paul H. Brookes Publishing; 2005:1-20.)

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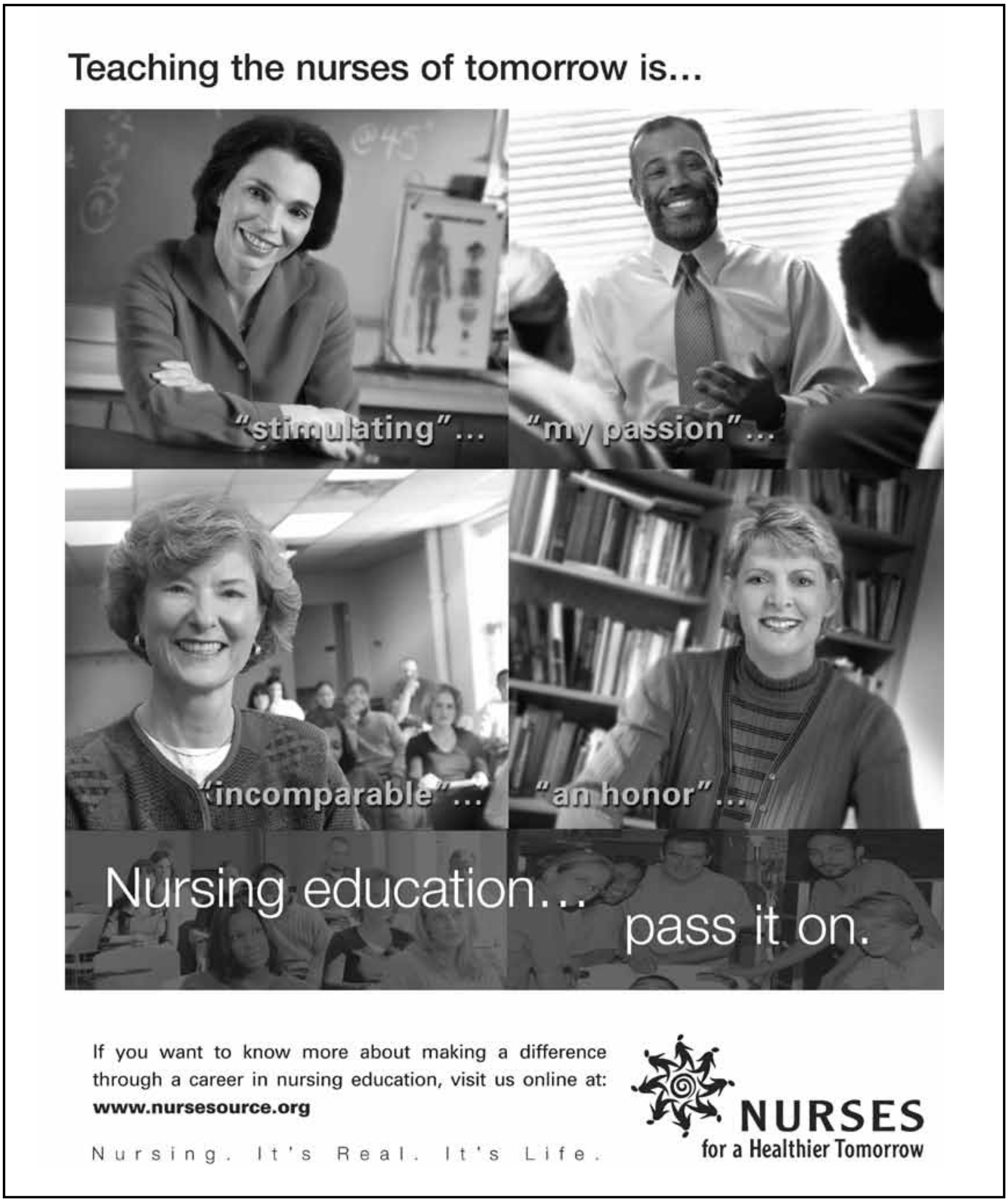

Embedding Developmental Disabilities into Medical Training

Irene Jurczyk; R. Bruce Kelly, MD

Until the 19th century, the care of persons with neurodevelopmental disorders/intellectual disabilities (ND/ID), and mental illnesses was largely left to the largesse, or lack thereof, of almshouses and state prisons. In North Carolina, a watershed mark was reached in 1848 when nursing crusader Dorothea Lynne Dix (1802-1887) visited the state. Where Governor Morehead had failed a few years earlier to persuade the legislature to fund the building of an institution for the humane care of individuals with significant mental disabilities, Dix succeeded. The first appropriations of $17,000 were made for the hospital's construction in 1849, and on February 22, 1856, the first patient was admitted to the new facility.[1]

By the beginning of the 20th century, North Carolina had three such facilities in operation, and the resident populations had expanded to include patients, often children, who presented with a wide range of mental, intellectual, and physical disabilities. World War I and the plight of veterans disabled by combat raised social awareness in a broader sense about barriers to access to a host of community, social, and health care privileges.[2] Continued advances in medical knowledge and systems of care, including the emergence of developmental pediatrics in the 1960s, led to increased life expectancies of children as well as adults with ND/ID. For example, "In the early 20th century the average life span of a person with Down syndrome was about nine years. A US study published in 2002 found that the median age at death of people with Down syndrome rose from 25 years in 1983 to 49 years in 1997."[3]

Today it is not unusual for those with significant developmental disabilities to live well into their 60s and beyond. In North Carolina, for example, at the Black Mountain Neuro-Medical Treatment Center the oldest resident is an octogenarian. With continued improvements, the life expectancy of most persons with ND/ID in the 21st century will approach that of the general population and, with appropriate supports that include patient-centered adult medical care, they will live significant and richly rewarding lives.

The deinstitutionalization movement, which began in the 1960s and continues through the present, created mechanisms of support for persons with ND/ID to move from large, state-operated residential institutions to community environments. The social integration model of care, while advantageous in terms of quality of life, has intensified the need for improved training of the health care workforce. The previous institutional model provided medical supervision, often overseen by a physician whose subspecialty was

> ***It is clear…that there will be no meaningful advancement in the care of adults with intellectual and developmental disabilities…without meeting the widespread call to develop not only a consensus curriculum across the learning levels, but also advanced training for those who want to subspecialize in adult developmental medicine.***

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psychiatry. However, at the community level, most adult primary care physicians and adult subspecialists have not been clinically trained or operationally prepared to receive persons with significant ND/ID into their practice settings.

A National Challenge

The need for improved clinical training of physicians in the care of persons with ND/ID has been evident since the 1989 Surgeon General's conference *Growing Up and Getting Medical Care: Youth with Special Health Care Needs*.[4] This initial conference report was followed by the 2001 Surgeon General's report on the need to integrate the mental health and primary care needs of persons with disabilities and by the landmark 2002 report *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation*.[5]

The 2002 report called for the health care system to "improve the quality of health care for people with mental retardation" and to "train health care providers in the care of adults and children with mental retardation." While these and other advances in the health care system have been considerable, standard medical education has yet to respond in a unified manner.

The office of the US Surgeon General expanded on the topic with yet another challenge five years ago. The 2005 *Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities* asks medical schools to "increase knowledge among health care professionals and provide them with tools to screen, diagnose, and treat the whole person with a disability with dignity."[6]

Indicative of the growing recognition of need, the National Institute of Medicine's 612-page text, *The Future of Disability in America*, was released in 2007.[7] In May 2009, the North Carolina Institute of Medicine issued its comprehensive report, *Successful Transitions for People with Developmental Disabilities*.[8] The report includes several recommendations for the legislature to support training of health care providers to work with persons with developmental disabilities. (See sidebar.)

More recently, the *Journal of the American Medical Association* carried a compelling commentary, "Educating Health Care Professionals to Care for Patients with Disabilities."[9] While not specific to ND/ID patients, the authors provide general guidance and recommendations for medical education to include disability education in medical training, following the six core competencies[a] defined by the American College of Graduate Medical Education (ACGME).

Responding to the 2005 Surgeon General's *Call to Action*, the American Academy of Developmental Medicine and Dentistry (AADMD) conducted a survey of all US-based medical schools and dental schools in 2005, with surveys

Successful Transitions for People with Developmental Disabilities:

A Report of the NCIOM Task Force on Transitions for People with Developmental Disabilities[8]

Recommendation 6.14: Training for Health Care Professionals

The Area Health Education Centers (AHEC) program, health professional schools, and Division of Mental Health, Developmental Disabilities, and Substance Abuse Services should work collaboratively with health professional associations, self-advocacy groups, parents, or parent advocacy groups to enhance the training provided to health professionals about providing services for people with intellectual and other developmental disabilities. The trainings should include, but not be limited to:

(1) Education for health care professionals (including physicians, dentists, nurses, allied health, and other health care practitioners) to provide better health care services for persons with intellectual and other developmental disabilities (I/DD).
(2) Establishing a primary care medical home for people with I/DD.
(3) Transitioning adolescents with I/DD from pediatric care to adult care and self-management.
(4) Training of psychiatrists, counselors, and other health care professionals in addressing the needs of individuals with I/DD who need mental health services.
(5) Education for health care professionals about the developmental disability system and how to coordinate services with the family, case manager, and other direct support workers to assist in providing proper health care for persons with I/DD.
(6) Internships and residency rotations in settings that routinely provide services to persons with I/DD.
(7) Support for continuation and expansion of mini-fellowships in developmental medicine.
(8) The North Carolina General Assembly should appropriate $150,000 on a recurring basis to the AHEC program to support these efforts.

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[a] The six core competencies adopted by the ACGME are: (1) Patient Care, (2) Medical Knowledge, (3) Practice-Based Learning and Improvement, (4) Interpersonal and Communication Skills, (5) Professionalism, and (6) Systems-Based Practice.

targeted to medical students, deans, and residency program directors. The report included the following key findings:[10]

- 77% of graduate medical education (GME) directors who responded reported no focus on ND/ID in their programs.
- 90% of GME directors reported interest in including ND/ID into residency training.
- 81% of medical students reported they received no ND/ID training.
- 74% of students reported interest in treating ND/ID patients in their future career.
- 100% of school of medicine deans reported interest in including ND/ID in the curricula.

Response in North Carolina

In 2004, the North Carolina Council on Developmental Disabilities issued a call for proposals to improve access and quality of primary care services for persons with developmental disabilities. The Mountain Area Health Education Center (MAHEC) responded and was awarded a three-year grant to conduct a review of the literature, survey stakeholders, identify specific educational needs, and conduct a range of continuing education programs to address them. The initial study indicated the need was greatest with respect to the care of adults with intellectual and developmental disorders. Implicit in the findings was the need for MAHEC to investigate the nascent field of adult developmental medicine.

Recognizing the limitations inherent in traditional continuing medical education activities to address the spectrum of needs identified by the surveys, MAHEC determined a "mini-fellowship" in an expanded, flexible learning format was a more realistic approach to effect change. The original concept was to offer training to faculty from the state's family medicine GME programs, the idea being that these faculty could serve as champions and mentors in sharing key elements of the training with medical students and residents. The lack of response was indicative of already overwhelming educational demands on the residency programs, and the invitation was extended to physicians in community practice. Ultimately, eight physicians from a variety of disciplines (including family medicine, internal medicine, medicine-pediatrics, and pediatric pulmonology) elected to participate. Among the group were physicians from New Mexico, Ohio, and Massachusetts—family medicine faculty who had learned of the North Carolina endeavor during the year-long curriculum development phase of the project.

The first cohort began in February 2007 with a three-day training orientation and overview of the 12-month experimental educational effort, the first of its kind in the nation. The course content included an immersion experience at the Orange Grove Center in Chattanooga, Tennessee, assigned readings, monthly meetings via live teleconference, self-study, didactic sessions, independent community learning, and opportunities for performance improvement projects. The goal for the first effort was to create a simple, replicable model that could raise awareness and highlight the collegiality and personal and professional rewards that would attract physicians to this area of work. The learning and fellowship exceeded expectations, concluding at the 2008 annual joint conference of the Developmental Disabilities Nurses' Association (DDNA) and the American Academy of Developmental Medicine and Dentistry (AADMD). It was at the DDNA/AADMD meeting that the concept of utilizing the MAHEC mini-fellowship to spearhead an effort to begin building a national consensus curriculum in adult developmental medicine emerged.

Prior to completion of the first cohort of the mini-fellowship, MAHEC was asked by the North Carolina Division of Public Health's Office of Disability and Health to participate in a statewide project to support the transition of youth with special health care needs from pediatric to adult medical home providers at age- and readiness-appropriate times for youth and their families. Three core components of the Carolina Health and Transition (CHAT) project were identified: (1) a health transition curriculum for the youth themselves, to prepare them for transfer of care and increasing self-management, (2) a parallel curriculum for parents and other significant persons in the youth's support network, and (3) a medical practicum with clinical toolkit to assist the referring and receiving physicians in the youth's transition to adult providers, as well as to coordinate the transfer of clinical, person-centered information from one provider to the next.

MAHEC, based on its experience in developing the mini-fellowship, agreed to assist the state with this new endeavor. Currently the CHAT project is in the third year of this novel effort, focusing on care coordination and quality improvement processes. MAHEC continues to partner with the state in this work and is also participating in a newly formed national transition research consortium created by Dr. Maria Ferris, a pediatric nephrologist and associate professor of medicine and pediatrics at the University of North Carolina at Chapel Hill School of Medicine.

An Ongoing Challenge

MAHEC continues to build upon the mutually collaborative relationships first forged with colleagues and organizations during the initial cohort of the mini-fellowship. Since that time, the Carolina Institute for Developmental Disabilities (CIDD) has emerged as a new leader in the field of developmental medicine in the state, and discussions on how the mini-fellowship can contribute to the Institute's mission are underway.

With funding from the Milbank Fund, exploratory work for the second cohort began in early 2009. A number of physician faculty who had already created innovative, effective teaching models in their own training programs and communities expressed interest in participating in MAHEC's efforts. A strong desire and eagerness to build a community of peers to advance their shared interests and passion for the work was readily apparent.

The North Carolina mini-fellowship, while unique, is but one in the latest series of attempts to create the foundation for physician training in ND/ID. There are at least a dozen initiatives in medical and community settings around the country attempting to incorporate adult primary care into their training, both for medical students and for residents, primarily through their family medicine departments. It is clear, however, that there will be no meaningful advancement in the care of adults with intellectual and developmental disabilities on a national level without meeting the widespread call to develop not only a consensus curriculum across the learning levels, but also advanced training for those who want to subspecialize in adult developmental medicine.

Knowing curriculum development will require a multi-year, multidisciplinary collaborative effort, the medical course director began to lay the foundation for a national collaborative to continue the curricular work. With the MAHEC mini-fellowship serving as an incubator project for this broader effort, the goals are to address the breadth of relevant issues, identify and review existing resources, and establish recommendations toward a national consensus on the inclusion of ND/ID content in medical education at the premedical, medical, and graduate medical education levels. (For a complete list of the coursework objectives, see sidebar.)

The second cohort, launched in September 2009, includes 20 fellows from 10 states, the District of Columbia, and Canada. Resources under review by the fellows are both comprehensive and international in scope. Utilizing a model developed through a federally funded grant to the Society of Teachers of Family Medicine to enhance education in nontraditional areas of primary care medical education,[11] and with the guidance of the project's distinguished advisory committee, the mini-fellowship will, over the next year, focus on answering the Surgeon General's *Call To Action* by developing steps toward the achievement of a national consensus on ND/ID curricular content at the premedical, medical, and graduate medical levels. Funding for 2010 has been provided by the North Carolina Council on Developmental Disabilities. With anticipated future funding from the Council and additional resources, the work will continue through 2012.

By adopting a consensus approach to the education of current and future physicians, the mini-fellowship hopes to serve as a focused, meaningful opportunity that will lead to improved health care, realized potential, and enhanced quality of life for persons with intellectual and developmental disabilities in North Carolina and beyond. **NCMJ**

For further information, contact the medical course director, Bruce Kelly, MD, at bruce.kelly (at) dhhs.nc.gov or the project director, Irene Jurczyk, at irene.jurczyk (at) mahec.net.

MAHEC Mini-Fellowship in Adult Developmental Medicine

Learning Objectives

The overarching focus is to effect change that will optimize the availability and quality of care to promote health for this medically underserved and often overlooked population. By the end of the mini-fellowship participants will have created a framework to:

(1) Build a community of peers to define and advance the field of adult developmental medicine.

(2) Review selected texts, articles, guidelines, existing educational efforts, and other related resources as appropriate to accomplish the above.

(3) Develop curricular recommendations with consideration given to scholarship, research, health care advocacy, cultural, economic, and policy interests for peer review, development, and dissemination.

(4) Define the steps necessary to implement the curricular recommendations across the spectrum of medical education.

(5) Create a vision and strategic plan for professional and academic relationships that will lead to implementation of these curricular resources.

(6) Establish a model for mentoring of peer and student learners beyond the mini-fellowship.

(7) Identify and cultivate steps needed for national sustainability of this curricular project.

(8) Use a web-based classroom to support this work by creating an enduring product that focuses on the above objectives.

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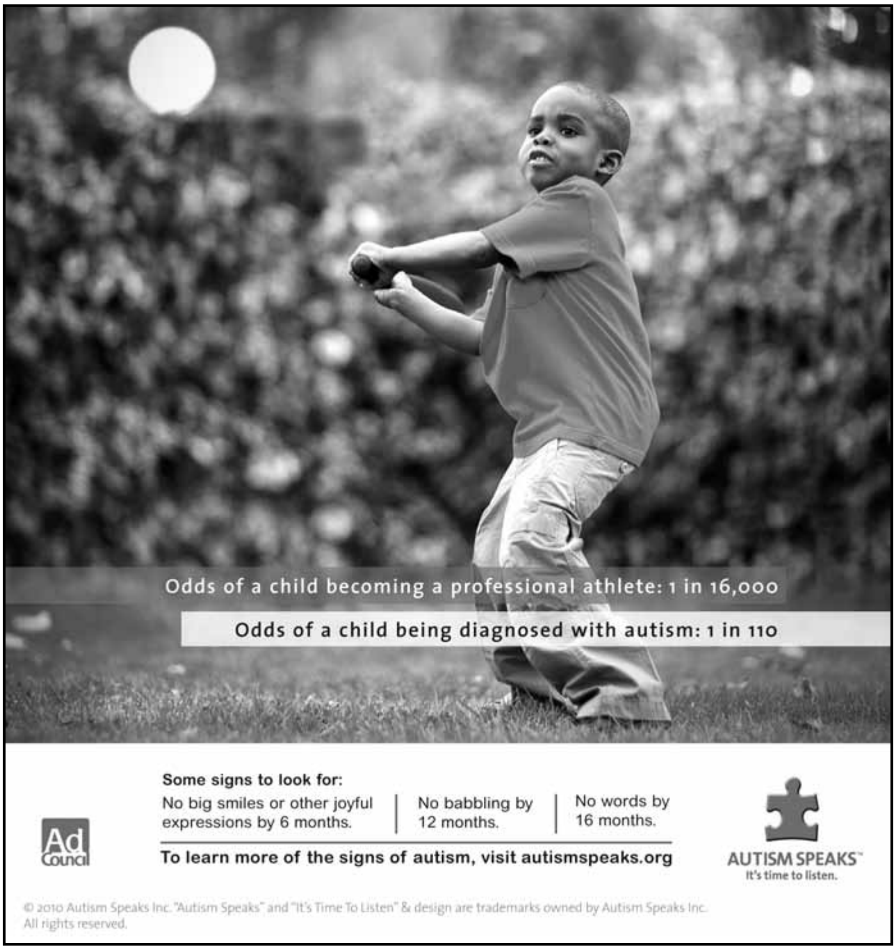

A Personal Perspective on the Future of the Developmental Centers in North Carolina

Alexander M. Myers, PhD, LP, HSP

"The future belongs to those who believe in the beauty of their dreams." —Eleanor Roosevelt

The future role of the developmental centers in North Carolina is a controversial topic. Discussions on this issue are always spirited, with opinions ranging from those who view the centers as sites of excellence in the field of service provision for the most needy of North Carolina's citizens with intellectual/developmental disabilities (I/DD), to those who abhor the centers' very existence and advocate for their elimination. I must acknowledge that I hold the former opinion. The views presented here may be shared by others, but are attributable solely to myself.

"The future ain't what it used to be." —Yogi Berra

Before forecasting the future, it is helpful to take a quick glance at the past and describe the role of developmental centers in the state's I/DD service delivery system. Prior to the 1970s, the centers (then known as training schools or institutions for the mentally retarded) were the primary residential option for this population outside of the family home. Conditions were deplorable by today's standards. In 1972, a new service known as intermediate care facility services for persons with mental retardation (ICF/MR) and related conditions was added to the Medicaid program. The introduction of this program allowed developmental centers to begin shifting their emphasis from warehousing clients to creating therapeutic homes that provided active treatment that prepared individuals to move back into the community.

"The future is here. It's just not widely distributed yet." —William Gibson

During the last 30+ years, developmental centers in North Carolina have downsized their resident populations and evolved into homelike communities while developing a unique expertise in serving persons with I/DD who have increasingly complex needs. The centers have served as a valuable public safety net for persons whose needs exceeded the available supports and services in the community.

North Carolina once had five regional developmental centers—it now has three. Black Mountain Center was converted into a neuromedical treatment center providing skilled nursing care a few years ago, and the O'Berry Center is in the process of transforming into a neuromedical treatment center also providing skilled nursing care.

> ***...until needed community resources can be established as safe and reliable and until providers demonstrate their willingness and ability to effectively serve even the most challenging individuals with I/DD, the services offered by the centers will be essential...***

The remaining three developmental centers have dramatically reduced their populations from their historic highs, working with Local Management Entities (LMEs) to prepare persons for life in a community setting. Caswell Developmental Center in the eastern region of the state has reduced its population from 2,045 to about 430. Murdoch Center in the central region has decreased from 1,660 to 525. The J.I. Riddle Developmental Center in the western region has seen its census lowered from 840 to approximately 350.

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It should be noted, however, that most of this downsizing occurred in the 1980s when community-based residential options were being developed. In recent years, community placements have become less frequent.

As they downsized, the centers continued to develop expertise in serving populations with significant challenges. Riddle Developmental Center is renowned for its cutting edge research and training in the area of I/DD and has recently developed a rapid response team in a collaborative consultative effort with Broughton Hospital, a state-operated psychiatric hospital. Caswell Developmental Center has developed a specialized, time-limited program serving adults with I/DD and mental illness. Murdoch Developmental Center is renown for its program library, its innovative vocational programs, and its three time-limited statewide specialty programs. These programs include (1) Partners in Autism Treatment and Habilitation (PATH), serving children age 6 to 16 with autism spectrum disorder and extreme behavioral challenges (this program includes two community PATH homes); (2) Specialized Treatment for Adolescents in a Residential Setting (STARS), serving adolescents age 13 to 17 with diagnoses of I/DD and mental health and behavioral issues; and, (3) Behaviorally Advanced Residential Treatment (BART), serving young adult males with I/DD and extremely challenging behaviors.

All three developmental centers are nationally recognized ICF/MR residential treatment facilities that continue to serve an ever-changing population. Each is now serving a general population of aging persons who primarily have severe/profound intellectual disabilities and who are viewed as hard to serve in the community due to either extreme medical needs or challenging behaviors. The list that follows gives the proportion of persons in the centers with each of the following needs:

- Severe/profound impairment (cognitive or adaptive) —97%
- Routine medications—99.4%
- Medications/treatments provided per day (Murdoch) —8,717
- Psychotropic medications—37.5%
- Non-ambulatory—33%
- Seizures—48%
- Fed by tube—14.4%

"Predicting the future is easy. It's trying to figure out what's going on now that's hard." —Fritz R. S. Dressler

Currently the developmental centers anchor the North Carolina service delivery system for persons with I/DD, providing specialized care and expertise for the most difficult to serve individuals. A strong, specialized training and consultation program providing support to the community was offered for many years until eliminated by the legislature several years ago. It was disappointing to lose this program as it helped maximize the effectiveness of community supports and prevented some admissions to the developmental centers. However, in their safety net role the centers continue to offer short-term therapeutic/diagnostic respite services to persons with I/DD when those services are unavailable in the community. The developmental centers have been especially important during the recent challenges presented by North Carolina mental health reform. During this period LMEs have gone through dramatic changes and the economy has worsened. The result is fewer dollars being available in the community to support persons with challenging behaviors. Also during this period the number of unserved or underserved individuals has continued to increase. In a time of great upheaval, the community has continued to depend on developmental centers as a source of stable services, as well as a nurturing home for many individuals with I/DD.

Moving Towards the Future

"We don't like their sound and guitar music is on its way out." —Decca Records rejects The Beatles in 1962

The persistent goal of some critics is the elimination of the developmental centers. However, until needed community resources can be established as safe, stable, and reliable and until providers demonstrate their willingness and ability to effectively serve even the most challenging individuals with I/DD, the services offered by the centers will be essential, especially given their specialty services. Given this reality, the centers are committed to the following:

1. Admissions committees at the centers will view the centers as placements of last resort. It is not easy to get someone admitted; LMEs must demonstrate that they have exhausted all community options.
2. Any person currently residing in the centers, regardless of level of need, could be served in the community if sufficient supports and resources are provided.
3. Active and persistent efforts have been and will continue to be made by the centers to work with families, LMEs, and providers to find adequate community placements for those who seek them.

While the developmental centers are committed to supporting community placement, a number of obstacles must be addressed. First, communication barriers must be eliminated. The LMEs, community providers, and the centers must share information about available openings, persons actively desiring placement, and the specific needs and supports for each individual. This collaboration must be maintained at least through a six-month transition period. Second, case management services during the transition process must be improved. Case managers must be skilled and available for thorough transition planning so they can work with the LME, the center, the individual/

family/guardian, and the chosen provider to develop and coordinate the transition plan. Third, both LMEs and residential providers need better incentives to move people out of the centers and into the community. Many LMEs see downsizing the centers as a low priority, given other pressing issues and the lack of resources. They tend to view the centers as providing a safe and secure home to individuals from their area and do not view them as a priority unlike those individuals in their catchment area who are underserved and who are clamoring for community-based services. Residential providers are also selective about who they serve. Not surprisingly, individuals with less complex support needs are easier and less expensive to serve than those coming out of the centers. Additionally, there is little disincentive for terminating a community placement for an individual with little or no warning when problems are encountered; this places the person in a crisis situation and the LME is often forced to turn to the developmental center (or the psychiatric hospital) for placement. There needs to be greater incentives for providers to continue to serve individuals who can be more challenging.

Fourth, families and guardians of individuals residing at the developmental centers also indicate a preference for continued center living. For many people, the centers have been home for many years; these people are aging in place and are content with their lives at the centers. The centers are viewed as stable, safe, and committed to person-centered programming; have ready and timely access to professionals, supports, and services; have relatively low turnover rates; and are protected by well-established advocacy programs, human rights committees, and continuous quality control protocols. Families and guardians are concerned that community providers are unable to meet the same standards as centers and as a result will not consider community placement. The community must acknowledge this mistrust and develop creative ways to reach out and build trust. Developmental center staff can continue to work with families and guardians to consider community options, but cannot build the needed trust. That must come from the community.

"I've read the last page of the Bible. It's all going to turn out all right." —Billy Graham

The developmental centers will continue to partner with the LMEs and other community providers to help North Carolina deliver top quality supports and services to citizens with I/DD. The centers should be considered as one part of a service continuum and serve as a safety net for people with significant I/DD. The centers' expertise can also be used to train direct care and professional staff in the community and students in the university system and to provide consultative support to families, LMEs, and providers. As the centers' population ages and community supports are strengthened, the centers will continue to become smaller and more focused on providing specialized services. Within 10 years, the centers will reach a point where their residential capacity represents a public safety net for persons with extreme I/DD needs within each of the three regions. Additionally, specialty programs for specific populations will help stabilize persons in crisis and help develop habilitative plans to assist community providers in the provision of long-term safe, secure, and therapeutic homes. Finally, working with community I/DD crisis teams (such as the new NC-START teams), LMEs, providers, advocacy groups, and the psychiatric hospitals, the developmental centers will replace emergency rooms, prisons, and the psychiatric hospitals as the last-resort safety net for persons in crisis. Working hand-in-hand to support all persons with I/DD, the goal will be to ensure safety, security, dignity, respect, and happiness throughout their lives in North Carolina. **NCMJ**

Don’t Fence Me In

Karen Stallings

Too often people see individuals with disabilities not as people, but as freaks. They don’t realize that people with disabilities have a lot to contribute to society by educating people about disabilities or how to advocate for one’s rights to live, work, and play in society against the odds. Whether people are disabled or not, everyone can contribute to their community and to society. If individuals would just stop and listen to people with disabilities, then they would realize that we have something to say.

They would see us in a different light. We are a people. We are different in a way. We may walk and talk differently, but we are just like everyone else in society. We have a body and soul, we have minds, and we know what we want to do with our lives. Some people with disabilities know what they would like to do with their lives. They would like to have real jobs with good pay. Some would like to live on their own or maybe with a roommate in their communities. People with disabilities are going to school. We are graduating from high schools and colleges to fulfill our dreams for our lives. Some may be doctors, attorneys, computer/software designers, actors, or actresses. We can be anything that we want to be in life, as long as we put our minds to the tasks at hand. This is true for anyone.

Take my job, for instance. I am an executive director of the Association of Self Advocates of North Carolina (ASANC) based in Raleigh. I have held that position for 12 years. ASANC works for self-advocacy and self-determination. We have a board of directors consisting of people with and without disabilities. We have a contract with the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services that we are governed by. As in any organization, we have board meetings to determine what decisions need to made for the Association. Although there are some individuals who may think—or have thought—that we couldn’t make decisions for our organization, nevertheless, we have made them.

I never thought I would become an executive director of a state organization, but it was a job that I believed in. So, I took a chance, and I was hired as the executive director. Just because I have 25% cerebral palsy with my speaking, walking, and fine motors skills, being affected doesn’t mean that I can’t work, live, or play in my community. I am active by being on other boards of directors now and in the past. I am a writer. I love to write. By writing and applying for a grant with the assistance of two friends, I created a newsletter for people with disabilities. My newsletter, *Disability Express, Inc*., has been in existence for 14 years, and it is still going strong. I am still proud of *Disability Express, Inc*. My husband and I have our own television show, “Speak Up, Speak Out, Voices in the Community” on Cable 10 through the Public Access Channel in Raleigh, North Carolina, which has been running for 10 years. The show is geared towards people with disabilities and topics that deal with legislative issues such as the People First Language Bill, that was passed, to emergency preparedness for people with disabilities.

My husband and I both act with the Raleigh Ensemble Players. I have run for city council four times, and even though I didn’t win, I did have a runoff. Some people recognized me as a candidate and some didn’t. Some people thought that my disability would interfere with my ability to hold a position in the city council. They saw my disability and not my ability to serve on the city council.

> ***When you see people with disabilities out and about in the community, remember, we are people, and we are enjoying life as well. If you stop and listen, we may learn from one another.***

I graduated from Irmo High School on June 3, 1975. While I was in high school, I didn’t let my disability get in the way of my learning, even though there were some people who believed that I shouldn’t have been in regular classes. They believed that I couldn’t keep up with the work or changing classes, but I showed them that I was capable of doing anything that I put my mind to doing. Of course, there were accommodations that had to be made for me in school such

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as note taking, locker opening, and taking tests, but once those accommodations were made, everything else was fine. I was voted "Miss Congeniality" by the senior class. Sure, some of the students made fun of me at school, but I tried to ignore them. If they didn't know me or didn't want to understand my disability, they weren't my true friends; my true friends knew me and understood me as a person. They saw me as their friend. Some of the students wanted to label me as "retarded" or "stupid," but I'm not a jar. Labels belong on jars, not people. After graduation from Irmo High, I attended the University of South Carolina in Columbia. My major was Early Childhood Development, and I graduated on May 13, 1978.

You would think that people with disabilities have certain privileges, receiving help with daily activities without difficulties. However, what if services such as Medicaid, SSI, and SSD were taken away? By taking supports and services away from people with disabilities, life for them wouldn't be so simple and easy. It would be rough for some, especially if they were dependent on those services to help with their financial needs on a regular basis. How would it be for people without disabilities to live that way? I imagine that they wouldn't prefer living with little or no money. Also, I bet many people without disabilities do live in some kind of daily financial struggle, but some won't let others know what trouble they are going through in their lives. It is hard with our economy as it is today. And it affects everyone whether they have disabilities or not.

Now, I would like to tell the story of my SSI check. I began receiving an SSI check when I started working in the late 1970s. My mom and I went to the Social Security office in Decatur, Georgia. We were told by a Social Security representative that as long as I didn't go over the amount of my current salary, I could keep receiving my SSI check for my entire working career. We were very happy and excited about hearing that news. Well, as life would have it, over the years my jobs changed and my salary changed. That was the good news. My salary was pretty decent, and I was still receiving SSI checks to help make ends meet. I thought things were fine, but Social Security saw things differently. I began having long disputes with Social Security over many years. It has been an uphill battle. Social Security wouldn't bother me for years then, suddenly, they would pop up out of nowhere and mail letters telling me that my SSI check would be taken away because of my salary being high, or saying I had to pay the money that I was receiving back to Social Security.

My dad, my husband, and I would have to go back to the Social Security office in Raleigh and speak with representatives about my SSI checks. It was often frustrating because some of the Social Security representatives wouldn't listen; but some would listen and they would try to be of assistance. It was as if I was going to a new drawing board every time I had to do battle with Social Security. It seemed like when my case was reviewed and discussed by the representative and myself, we could get the kinks worked out and get back on track with me receiving my checks. To say the least, once more I was happy and relieved that the battle with Social Security was finished for the moment. I could continue living my life with some ease due to my Social Security checks. I was paying my bills without really worrying about not having enough money for my living expenses.

Even though everything worked out with Social Security for a period of time, a monkey wrench was thrown into the works once again. In 2003, the battle started again with Social Security. As hard as I tried, I couldn't win that battle. Social Security finally took my checks in 2003 because my gross income was too high. It wasn't quite fair. I realize that the government needs money to be paid back by citizens, but I am trying to contribute to the community by working just like everyone else. However, Social Security doesn't see it that way. All they are concerned about is their money and how people are going to pay them back.

I have known friends and coworkers who have lost their benefits along with services just because they wanted to get married and live in the community of their choice. They would like to contribute to communities as taxpayers, but it's especially hard when Social Security won't work with people with disabilities and let them receive their checks. It could make their lives simple. People with disabilities face living without assistance to help them live their daily lives. Their services are being cut due to not enough money in the state's budget. I'm asking you, is this fair? No, it isn't fair. People with disabilities shouldn't be penalized because they want to live, work, and play in society.

We will keep fighting for our rights until our voices are heard throughout the community. When you see people with disabilities out and about in the community, remember, we are people, and we are enjoying life as well. If you stop and listen, we may learn from one another. Please don't let our voices be silenced any longer. Hear what we are saying to our communities. **NCMJ**

Resources for Individuals with Intellectual and Other Developmental Disabilities and Their Families

Catherine E. Liao

The following is a list of resources available to individuals with intellectual and other developmental disabilities and their family members, advocates, and health providers. The organizations listed below offer services that range from providing direct services to individuals in North Carolina to advocating on national, state, and local policy issues. Information presented here was obtained from each organization's website.

This list is not exhaustive and is meant to provide examples of the types of resources available statewide. More information on additional membership and provider organizations is available at http://www.nc-council.org/members and http://www.ncproviderscouncil.org.

Association of Self Advocates of North Carolina

Established in 2000, the Association of Self Advocates of North Carolina (ASANC) is a nonprofit organization working to promote self-advocacy and self-determination in individuals with developmental disabilities across the state. ASANC is dedicated to enabling, educating, encouraging, and empowering individuals with developmental disabilities to become active members in their communities and in society.

http://www.asa-nc.org

Autism Society of North Carolina

Founded in 1970 by parents of children with autism spectrum disorder, the Autism Society of North Carolina (ASNC) advocates for individuals with autism and their families to ensure community support and services are available for everyone within the autism spectrum. ASNC offers support for family members, health care practitioners, educators, other professionals, and individuals through an online bookstore, newsletter, trainings, and resources for vocational, educational, residential, and mental health services.

http://www.autismsociety-nc.org/index.php

Beyond Academics

In partnership with the University of North Carolina at Greensboro, Beyond Academics is a four-year post-secondary education program for adults with intellectual and other developmental disabilities. Classes in meal preparation, relationships, and personal safety, among others, are enhanced by peer-to-peer training through a campus and community support program.

http://www.beyondacademics.org

Center for Development and Learning, Carolina Institute for Developmental Disabilities, University of North Carolina at Chapel Hill

The Center for Development and Learning (CDL) was established in 1962 to provide a range of clinical services for children and adults with developmental disabilities and their families. Housed in the Carolina Institute for Developmental Disabilities, the CDL is the state's Center of Excellence in Developmental Disabilities. Every year, the CDL serves more than 1,500 children, adults, and families through clinical evaluation services and provides training to more than 200 trainees, families, and professionals in the community.

http://www.cdl.unc.edu

Disability Rights North Carolina

Disabilities Rights North Carolina (DRNC), formerly known as Carolina Legal Assistance, is part of a national system of federally-mandated independent disability agencies. DRNC is the only statewide legal nonprofit disability advocacy organization serving all persons with disabilities.

http://www.disabilityrightsnc.org

Easter Seals UCP of North Carolina

Easter Seals UCP of North Carolina was created in 2004 by a merger between Easter Seals North Carolina and UCP (United Cerebral Palsy) of North Carolina. The Easter Seals UCP website provides detailed information on services that include child development, therapy, community inclusion, residential living, supported employment, in-home and community-based supports, respite care, disability benefits counseling, information and referral, and advocacy.

http://nc.easterseals.com

Exceptional Children's Assistance Center

The Exceptional Children's Assistance Center (ECAC) provides information, outreach, and support on educational issues to parents and families of children with disabilities. Projects and programs in early childhood development, education, health, and leadership offer parents, educators, and other professionals information about how to best advocate for children with disabilities. More information on the services provided by the ECAC, including a toll-free parent hotline, parent education workshops, and an online lending library, is available on its website.

http://www.ecac-parentcenter.org

First in Families of North Carolina

First in Families of North Carolina offers support to individuals with developmental disabilities and their families through the provision of recreational items, home furnishings or modifications, childcare or respite care, and vehicle repairs, among others. Other support includes connecting individuals to vocational, social, and educational opportunities with the goal of full inclusion in the community.

http://www.firstinfamiliesofnc.org

Life Plan Trust

Life Plan Trust, a service offered by The Arc of North Carolina, NAMI North Carolina, the Autism Society of North Carolina, and Easter Seals UCP of North Carolina, assists North Carolina families of individuals with developmental disabilities, mental illness, and other disabilities with developing comprehensive plans for future care. More information about the services offered is available under "Commonly Asked Questions" of the Life Plan Trust website.

http://www.arcnc.org/services/life_plan_trust

Local Management Entities

The North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (MHDDSAS) oversees Local Management Entities (LMEs), which are agencies of local government responsible for managing, coordinating, facilitating, and monitoring the provision of mental health, developmental disabilities, and substance abuse services in catchment areas across the state. LME responsibilities include offering complete access to services, developing and overseeing providers, and addressing consumer complaints and grievances.

http://www.dhhs.state.nc.us/mhddsas/lmedirectory.htm

North Carolina Consumer Advocacy, Networking, and Support Organization

The North Carolina Consumer Advocacy, Networking, and Support Organization (CANSO) is a self-advocacy organization working to represent and address the needs of individuals with mental illness, developmental and cognitive disabilities, and diseases of addiction.

http://www.nc-canso.org

North Carolina Council on Developmental Disabilities

The North Carolina Council on Developmental Disabilities (NCCDD) is an independent agency within the North Carolina Department of Health and Human Services. As a 34-member, governor-appointed body, 60% of its members are people with developmental disabilities or family members of people with disabilities. NCCDD provides funding for projects and advocates for system changes that promote the full inclusion of all people with developmental disabilities in community life.

http://www.nccdd.org

North Carolina Department of Health and Human Services

The North Carolina Department of Health and Human Services (DHHS) is responsible for ensuring the health, safety, and well-being of all North Carolinians. Among other duties, DHHS provides human service needs for individuals with mental illness and intellectual and developmental disabilities. Several divisions and offices within DHHS share responsibility for providing these services to different subpopulations.

http://www.dhhs.state.nc.us

Other divisions and offices in DHHS include:

Division of Child Development
http://ncchildcare.dhhs.state.nc.us/general/home.asp

Division of Services for the Blind
http://www.dhhs.state.nc.us/dsb/index.htm

Division of Services for the Deaf and Hard of Hearing
http://www.dhhs.state.nc.us/dsdhh

Division of Mental Health, Developmental Disabilities, and Substance Abuse Services
http://www.dhhs.state.nc.us/mhddsas/index.htm

Division of Vocational Rehabilitation
http://dvr.dhhs.state.nc.us

Office of Education Services
http://www.ncoes.net

North Carolina Disability Action Network

The North Carolina Disability Action Network (NCDAN) has been working to empower individuals with disabilities since 2002 and is currently establishing itself as an independent nonprofit organization. As a statewide organization with more than 800 members from nearly 80 counties, NCDAN has developed a sophisticated communication system through its grassroots network. The Network provides comprehensive training, connect individuals with disabilities with policymakers and other advocacy efforts, and collaborate with other local and statewide organizations working in the disability community.

http://www.ncdan.org

North Carolina Statewide Independent Living Council

The Statewide Independent Living Council (NCSILC) describes its mission as "promoting a philosophy of independent living, including a philosophy of consumer control, peer support, self-help, self-determination, equal access, and individual and systems advocacy, in order to maximize opportunities for individuals with disabilities and the integration and full inclusion of individuals with disabilities into the mainstream of society." NCSILC aims to meet its mission by working with the North Carolina Division of Vocational Rehabilitation and the North Carolina Division of Services for the Blind to develop and execute the State Plan for Independent Living (SPIL).

http://ncsilc.org

The Arc of North Carolina

The Arc of North Carolina is a nonprofit organization working with and for people with disabilities. Its Community Supports program provides personal assistance, independent living, and supervised living services, as well as transportation training and assistance and coaching in self-advocacy. The Arc of North Carolina also actively advocates for people with disabilities and their families on the federal, state, and local levels.

http://www.arcnc.org

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Spotlight on the Safety Net

A Community Collaboration
Kimberly Alexander-Bratcher, MPH

Guilford Child Health, Inc.

Guilford Child Health, Inc. (GCH) is a model pediatric practice providing general and specialty care for children from birth through adolescence. This private, nonprofit practice mainly serves children in families with incomes at or below 200% of the federal poverty guidelines. In addition to day-to-day concerns about their children, these families also experience the added stress of low socioeconomic status. By using a medical home approach, Guilford Child Health is able to commit to providing the highest quality care while embracing an outlook that is compassionate and inclusive for their patients and their families.

In 2000, Guilford Child Health received a Commonwealth Fund grant to begin the North Carolina Assuring Better Child Health and Development (ABCD) project. One of only four states funded nationally, North Carolina used the Community Care of North Carolina networks to build from a single quality improvement project targeted to children in one network (including GCH) to 11 networks during the third year of the grant and subsequently move the program statewide. The ABCD project was designed to better integrate services for children with developmental needs. It incorporated two components: (1) a standardized screening tool (Ages and Stages Questionnaire) used at selected well-child visits, and (2) collaboration with local and stage agencies and families to develop a system to identify and serve children with developmental needs.

Developmental screening has always been an important initiative for Guilford Child Health. In 1999, when the practice first began tracking screening efforts, staff used the Denver Screening tool that required 20 to 30 minutes of staff time and cooperation of the child. Because of the time needed to complete the exam, few children—mostly those who were suspected of having a developmental delay—received the screening. Through the ABCD project, GCH began using the Ages and Stages Questionnaire. This tool involves parents by having them report on their child's development. It is easy to score, has excellent sensitivity and specificity, and fits easily into the practice flow. Moreover, it recognizes the parents as experts on their child and involves them in the decision-making process regarding the child's health, development, and other needs. Guilford Child Health is one of the few pediatric practices that is able to document the long-term effectiveness and benefit of developmental screening.

Dr. Marian Earls, medical director of GCH and developmental pediatrician, notes "using this tool allows the parents to become a partner in the visit and the visit is more family-centered. When a parent understands their child's behavior, they are better able to understand how to manage that behavior." Other providers in the practice note that having the tool completed before the visit helped them focus on the needs that parents identified and work together with the parents to develop solutions.

Collaboration and teamwork are major factors in the success of the ABCD project. GCH has developed relationships with many local and state agencies through wraparound services. The GCH provider team meets regularly with representatives of WIC, children's developmental service agencies (CDSA), Guilford County Department of Social Services, Guilford County schools, child service coordination, school health nursing, community nursing, and family planning. The meetings help link families with available resources and provide some continuity between agencies.

Since the inception of the ABCD project, Guilford Child Health has built upon the initial structure to offer a wider range of integrated services to all its patients and families. The ABCD screening is identifying children with developmental delays at earlier ages and physicians are the largest referral group to services for children ages 0-3 through the CDSA. This allows children to get appropriate services and support earlier in their development. The ABCD screenings are now more comprehensive, including social and emotional development and maternal depression screenings during the two and four month well-child visits. In addition, screenings for school age and adolescent patients that include components of development, learning, and psychosocial issues are a routine part of well-visits. GCH has an integrated program with developmental pediatricians, a child and adolescent psychiatrist, a speech and language pathologist, and licensed clinical social workers.

These provider teams can work with patients at the same time to deal with psychosocial or mental health issues, all while in the relative comfort of the primary care practice. An integrated pediatric neurologist is available one half day per week and specialty consultations are available on-site. GCH was a participant in the mental health integration project through Community Care of North Carolina (CCNC). GCH providers utilize care managers from the CCNC network who extend care into community.

The primary care services have also become more integrated. The primary care providers and licensed clinical social workers have a team-directed care clinic one half day per week so that patients with chronic conditions or developmental delays can have longer visits. Community liaisons help patients set up appointments, arrange transportation, link them to resources like childcare or summer camp, facilitate and track referrals, and help families navigate the often complicated, disjointed health care system. The specialty staff has grown from a pediatric neurologist and asthma and developmental pediatricians to include licensed clinical social workers, a child psychiatrist, a child psychologist, and nutritionists.

Initially, Guilford Child Health focused on building systems of care in order to meet the special needs of children with developmental disabilities and chronic diseases, but the improvements in integration benefit all children in the practice. The integration of services facilitates healthy relationships with families. GCH uses a comprehensive approach so that families can access many services in the practice. Great working relationships with resources in the community offer benefits to families rather than just a phone number to call. The GCH providers strive to treat the whole child in the context of family, school, and community.

Marian Earls, MD, FAAP, medical director of Guilford Child Health, Inc., contributed to this article.

Running the Numbers

A Periodic Feature to Inform North Carolina Health Care Professionals about Current Topics in Health Statistics

From the State Center for Health Statistics, North Carolina Department of Health and Human Services
http://www.schs.state.nc.us/SCHS

Children with Special Health Care Needs in North Carolina

As defined by the federal Maternal and Child Health Bureau (MCHB), children with special health care needs (CSHCN) are those children ages 0-17 years that are at elevated risks for chronic developmental, physical, emotional, or behavioral conditions that generally need health and related services beyond those required by children in general.[1] This definition includes children with birth defects, asthma, autism, attention deficit disorder, developmental disabilities, and other chronic conditions. More than 10.2 million children in the US are affected by these conditions, with prevalence rates ranging from 10%-22%.[1,2] The prevalence can vary according to multiple factors, including the child's age, gender, race/ethnicity, and residential location, as well as the specific criteria used to define CSHCN by different surveys.[2]

In North Carolina, the Child Health Assessment and Monitoring Program (CHAMP) survey provides ongoing state-specific information on various aspects of the health of children ages 0-17, including CSHCN. The CHAMP survey was initiated in the fall of 2004 and has been implemented annually since January 2005. Conducted in both English and Spanish, the CHAMP surveys are revised each year to meet the evolving child health surveillance needs of North Carolina.

Eligible children for the CHAMP survey are drawn at random each month from the North Carolina Behavioral Risk Factor Surveillance System (NC BRFSS) telephone survey of adults ages 18 and older. All adult respondents with children living in their households are invited to participate in the CHAMP survey. One child is randomly selected from the household, and the adult most knowledgeable about the health of the selected child is interviewed in a follow-up survey.

Questions on the CHAMP survey cover a variety of health related topics, including early childhood development, access to health care, oral health, mental health, physical health, nutrition, physical activity, family involvement, and parent opinion on topics such as tobacco and childhood obesity. In general, these domains are comparable to the ones found in the National Survey on Children's Health (NSCH). Data on these health issues are broken down by various demographic and risk groups, including CSHCN. Prior to 2008, the definition of CSHCN in the CHAMP survey included children in need of prescription medications. However, in the 2008 survey, use of prescription medications was dropped as a criterion for CSHCN, therefore the CHAMP results prior to 2008 are not comparable to those presented here.

Table 1 shows selected characteristics of special needs children as reported in the CHAMP survey. An estimated 9.8% of North Carolina children were considered to be special needs children according to the 2008 survey. Males were more likely than females to be classified as CSHCN as were white children compared to African American and other minority children. Children ages 14-17 were about twice as likely to be classified as special needs compared to children under age five. The majority of CSHCN currently had health insurance coverage through Medicaid, NC Health Choice, or private providers. Only a small number of respondents indicated that their child had no current health insurance coverage.

As expected, CSHCN were more likely to experience various chronic health and medical conditions compared to their non-CSHCN counterparts. They were more than seven times as likely to have their general health status rated as "fair" or "poor" by their parents, were more likely to weigh either below the 5th percentile or above the 95th percentile for children of a similar age, and were more likely to have dental problems (see Figure 1, page 572).

Table 1.
Demographic Characteristics of Children with Special Health Care Needs, North Carolina Child Health Assessment and Monitoring Program (CHAMP), 2008

	Number[a]	Percent[b]	95% CI[c]
Total	**297**	**9.8**	**8.6-11.2**
Gender			
Male	172	11.4	9.5-13.5
Female	125	8.2	6.6-10.1
Age (years)			
< 5	43	6.0	4.2-8.5
5-10	102	11.1	8.9-13.8
11-13	51	10.8	7.8-14.8
14-17	101	12.1	9.6-15.3
Race			
White	226	11.5	9.9-13.4
African American	32	7.7	5.3-11.3
Other	39	6.6	4.4-9.8
Parent's Education			
< High School	11	4.4	2.1-9.1
High School	57	11.4	8.3-15.3
Some College	94	12.8	10.0-16.2
College Graduate	135	8.9	7.3-10.8
Child's School Grade			
Not in School	44	6.5	4.6-9.1
K-5	106	10.2	8.1-12.6
6-8	56	12.2	8.9-16.4
9 and Above	91	11.9	9.3-15.1
Current Health Insurance Status[d]			
State Health Plan	11	5.3	2.7-10.1
Private	123	7.2	5.8-9.0
NC Health Choice	26	16.1	10.3-24.3
Medicaid	101	15.7	12.6-19.5
Other Insurance	25	11.4	7.3-17.4
No Health Insurance	10	6.0	3.0-11.7

[a] Total number of respondents to survey=2,959.

[b] The percentages shown are weighted percentages, designed to reflect the entire population of North Carolina children ages 0-17.

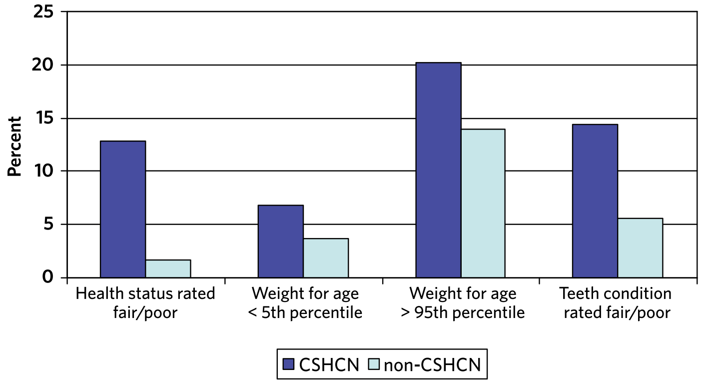
[c] 95% CI=95% confidence interval.

[d] First column totals 296 instead of 297 due to one invalid response.

School performance issues are also reported to be more common among CSHCN than non-CSHCN (see Figure 2, page 572). Special needs children were more than twice as likely to miss two or more weeks of school and to have repeated a grade. CSHCN were also less likely than non-CSHCN to make A's and B's and were more likely to have made mostly C's or lower during the past year.

Based on the 2008 CHAMP survey data, CSHCN do not appear to have problems with either access to or use of health and medical care compared to their non-CSHCN counterparts (see Figure 3, page 573). CSHCN were only about one-half as likely as non-CSHCN to have no health insurance currently or within

Figure 1.
Selected Health Indicators for CSHCN* and non-CSHCN, Ages 0-17, NC CHAMP Survey, 2008



* CSHCN: Children with special health care needs.

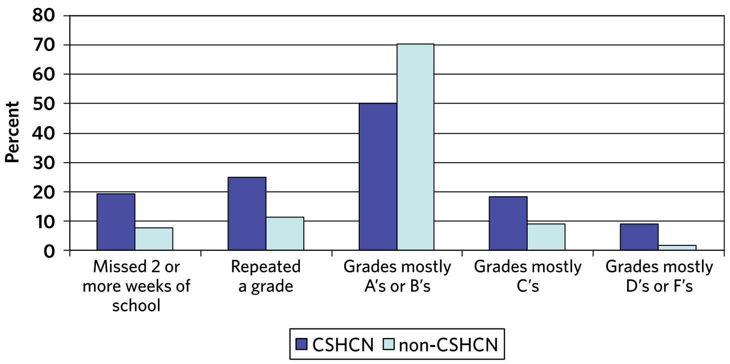
the last year. They were also less likely to have no personal doctor/nurse and to have no regular dentist or dental clinic compared to non-CSHCN. About 13% of CSHCN did not receive well-child care during the past 12 months, compared to about 15% for non-CSHCN.

The overall prevalence of CSHCN in the 2008 CHAMP survey is lower than the estimated percentage of 15.4% for the state, based on the 2005-2006 National Survey of Children with Special Health Care Needs.[3] However, the prevalence of CSHCN from CHAMP is very similar to the prevalence from the National Survey of Children's Health (9.6%), based on the single criterion of increased need for services. Beginning in 2010 the CHAMP survey will use a definition of CSHCN that is more similar to that of the National Survey of Children with Special Health Care Needs, so the two surveys should yield more comparable results.

The 2008 CHAMP results for health care access and insurance coverage are in line with those of the National Survey of Children's Health. Although the percentage of children having health insurance does not differ greatly between CSHCN and non-CSHCN, the type of insurance coverage does. CSHCN are more likely than non-CSHCN to use government-funded services such as Medicaid or NC Health Choice. Furthermore, earlier findings from CHAMP suggest that even though CSHCN and non-CSHCN had similar rates of insurance coverage, the amount of coverage for CSHCN was often inadequate. For example, parents of CSHCN were more likely to say that their child did not receive all of the medical care needed in the past year and, for instance, did not get a prescription filled due to cost. This suggests that although these families have coverage, it is inadequate. These questions were not included in the 2008 survey, so it is not clear whether these issues persist.

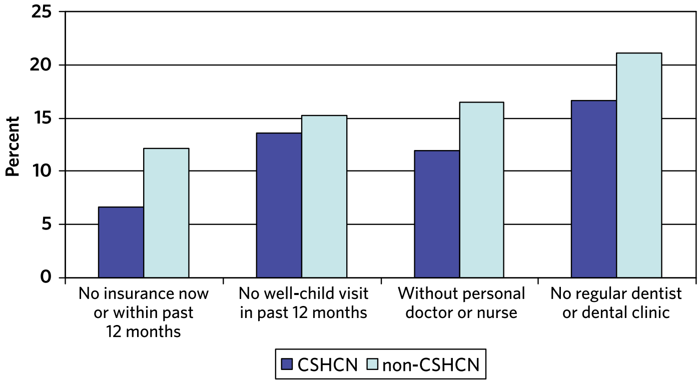
The results from the 2008 CHAMP data are contradictory to other studies on CSHCN, including results for North Carolina from the National Survey of Children with Special Health Care Needs. Several of these studies have demonstrated that health and medical service use and costs for CSHCN vary considerably across different chronic conditions and service use categories such as inpatient, physician, and outpatient services.[4,5] Studies have also demonstrated that

Figure 2.
School Performance for CSHCN* and non-CSHCN, Ages 4-17, NC CHAMP Survey, 2008



* CSHCN: Children with special health care needs.

Figure 3.
Health Care Access and Utilization for CSHCN* and non-CSHCN, Ages 0-17, NC CHAMP Survey, 2008



* CSHCN: Children with special health care needs.

minority children with special needs have greater difficulty in accessing health care and have poorer health status than white CSHCN.[6,7] They also experience differences in insurance coverage and health service use.[6,7]

Several reasons exist for the discrepancies of results in the 2008 CHAMP data and previous studies on CSHCN. These include the wording of the survey questions with regards to special needs and sample size. The CHAMP results also need to be interpreted with caution due to the wide confidence intervals, resulting from the small sample size. Additional years of data will improve the precision of the sample estimates. Despite this limitation, the CHAMP data provide more specific state-level information than the National Survey of Children with Special Health Care Needs.

Improving access to services and resources for CSHCN is an important public health goal that is necessary for improving the health and quality of life of children and individuals with special needs. Health care providers, health insurance companies, and health departments should work collaboratively with families and existing health care systems to provide adequate coverage for needed services for CSHCN. Future reform in health care should consider accessibility of services for families with children with special needs and the various mechanisms available for adequate coverage of services. Improving social networks of families of CSHCN may help alleviate the stress many families experience by connecting them with local support groups and other community resources. Additional training and continuing education for health professionals would help them better serve families of children with special needs.

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Readers' Forum

To the editor:

Solo and small group mental health care professionals are often the only care options for rural and isolated clients. It's about time that the independent solo or small-group providers be accorded some measure of respect for their efforts.

The July/August 2009 issue of the *North Carolina Medical Journal* does a good job of covering medical care issues across the state, including mental health care. However, there appears to be no organizing meta-statement as to how health care ought to be implemented in North Carolina. The articles indicate that for-profit health care has, understandably, an agenda of creating more business—as long as it is paid—while the nonprofits or charity health care providers are turning away patients. For the smaller practices we are forced to be content with patients and funds that "trickle-down" to us. The voices of the solo and small group providers were not present in the *Journal's* issue.

North Carolina mental health reform was instituted in 2001, with implementation starting in the furthermost point from Raleigh in western North Carolina where it was created. I was at quite a few of the provider meetings held by the Smoky Mountain Center LME in Sylva, NC. Dozens of interested providers were present at those meetings. What took place provides a window into what has happened over the past eight years and what will, I believe, increase—smaller, more flexible providers are supplanted by larger companies that provide a wider range of lower grade services. That's how they make their money. Individual therapy and assessment becomes formatted group therapy rendered by lesser qualified mental health professionals. Big fish eat little fish and bigger fish eat them. As we all know, for-profit means that the people at the very top earn a great deal of money. I do not see any trickle-down effect for the payment of people doing the actual work.

As a psychologist, my fee-for-service practice allows me to be paid reasonably well for my time in working with mostly Medicare and Medicaid indigent clients. As a clinical/health psychologist, my training allows me to create something of a 'mini medical home' as I link patients to the most appropriate providers given their physical and mental health challenges.

North Carolina mental health reform could perhaps been seen as stumbling vaguely towards the creation of total health care clinics. In 2001, the community mental health centers became administrative entities of mental health care. However, private providers would need to be folded into entities providing more than just mental health services. Thus, universal health care becomes something more than just health insurance available for any and all citizens. Undeniably, we have been on this fee-for-service path for decades and I might speculate that it will take a generation or two of practitioners for this to change.

A bittersweet moment took place several years ago in western North Carolina as former director of MHDDSAS, Michael Moseley was speaking to a small audience at Western Carolina University, describing the emperor's new clothes in terms of how well North Carolina mental health reform was moving along. This was the same day that the largest private company, which insured 10,000 for mental health care, was collapsing two counties over.

The chaotic churn of the disinvestment, which could have been anticipated but not avoided after the fact, coupled with the refusal or inability of the LME's utilization review departments to authorize and reimburse for mental health care for uninsured, state-funded clients as rendered by willing, independent providers, has not just dissuaded me, but blocked me from working with this patient population.

One of the original tenets of North Carolina mental health reform, which sits at the heart of insurance policies associated with choice of providers, is to support the livelihood of the smaller providers who work outside the mainstream currents. While the *Journal's* issue was devoted to blocks of providers, be they within private, for-profit companies, or working at free clinics, bear in mind the usefulness of providers who have their limited number of fingers plugged into the holes of the dyke.

Marsha V. Hammond, PhD,
Licensed Psychologist

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Health Reform: An Invitation to Contribute to the Discussion

The run up to the November election brought a lot of attention to health reform. Both major candidates presented relatively complete plans for major changes in the way we pay for health care and how we structure our health care delivery system. The appointments by President Obama point to a sustained effort to implement real change. This has prompted many experts and representatives of patients, providers, and payers to propose their own plans for reform. The *North Carolina Medical Journal* will be taking a part in this discussion with a section of the *Journal* devoted to articles and analyses that focus on reform. We would like to invite submissions that help the readership of the *Journal* understand why reform may be necessary, how the system should be changed, and how national reform will affect North Carolina. We invite scholarly discussions and analyses as well as commentaries that help illustrate the benefits as well as the problems that comprehensive change will bring to the costs, quality, and outcomes of health care and to the health of the people of North Carolina. The sixth installment of this series starts on page 513 of this issue of the *Journal*.

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