



BRIDGES

NC Council on Developmental Disabilities



Educating and Pushing for Change— A Capitol Hill Experience

by Dawn Douglas

Council members **Lawrence Shockey** and **Rosemary Bernauer** and Executive Director **Holly Riddle** represented the North Carolina Council on Developmental Disabilities at the Disability Policy Seminar 2005 Partnership



(Pictured 1 to r), **Ellen Russell** (Arc of NC), **Diane Loy** (Arc of Johnston County), **Lawrence Shockey** (NC Council on Developmental Disabilities Council member and Arc of Johnston County), **Dale Bender** (Arc of Johnston County) and a legislative staff member take advantage of the opportunity meet at Congressman **Bob Ethridge's** office in Washington, D.C. Congressman Ethridge represents the 2nd District of North Carolina (Chatham, Cumberland, Franklin, Harnett, Johnston, Lee, Nash, Sampson, Vance and Wake).

for Empowerment in Washington, D.C., February 28 through March 2. The seminar, hosted by The Arc of the United States, the American Association on Mental Retardation, the Association of University Centers on Disabilities, United Cerebral Palsy and the National Association of Councils on Developmental

Disabilities, focused on education and awareness of public policy issues that critically impact people with various disabilities, their families and supporters.

The NCCDD also had the opportunity to present findings and make recommendations that influence the lives of the disability community to policymakers. *(continued on page 6)*

Issues addressed included:

- Long-term services and supports
- Direct-support workers
- Medicaid
- Housing for people with disabilities
- Fiscal year 2006 budget and appropriations
- Civil rights
- Temporary assistance for needy families
- Social security reform
- Transportation
- Employment

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Chair's Message: Looking Back

After four years as the NCCDD chair, it's time for me to step down to devote more time to work. I've been proud to lead the Council as it selected and

funded cutting-edge projects that directly affect people with developmental disabilities and their families. Not only have our projects made a difference in their lives, but our efforts have also assisted the entire disability community and strengthened communities in general.

The Council's initiatives are as diverse as the people we serve. These projects range from arts to access, health to business, system change to community partnerships. The breadth of these projects mirrors the breadth of the disability experience. Some projects that make me especially proud include:

Advocacy: Council-funded projects continue to educate people with developmental disabilities and their families to be better self-advocates. The North Carolina Disability Action Network (NC DAN) gives people with disabilities a way to get more involved in civic life. Partners in Policymaking gives people with developmental disabilities and families the skills necessary to have an effective voice in their cities, counties and states. The Council also created an advocacy guide to help people navigate the political and bureaucratic systems we often face.

Healthcare: Through projects such as Access to Dental Care for People with Developmental Disabilities and Access to Primary Healthcare Initiative, more people with developmental disabilities are receiving the healthcare they need, and doctors and dentists are learning how to provide care to people with developmental disabilities. These projects can be replicated to help diminish healthcare disparities experienced by others with disabilities.

System reform: Collaborations with Local Management Entities (LMEs), including Making System Reform Work for People with Disabilities and Ecology for Change. Focus on increasing the capacity for people with disabilities and their families to develop the skills to be leaders in the state's new Mental Health/Developmental Disabilities/Substance Abuse Services system.

Justice: We have worked to improve the outcome for people with developmental disabilities who have to interact with the criminal justice system. In the N.C. Partners in Justice initiative, people with developmental disabilities learn about the justice system, how to avoid it and how to respond when involvement becomes necessary. Through the Guardianship and Quality of Life project, we have also worked with the justice system to ensure that limited guardianship is considered a viable option for

people with developmental disabilities by the courts.

It's been a very good four years, and I appreciate the opportunity to have served the Council and North Carolina's citizens with developmental disabilities and their families as Council chair.

Even though I'm stepping down as chair, I plan to continue to serve in a leadership capacity with various Council projects. It's been a very good four years, and I appreciate the opportunity to have

served the Council and North Carolina's citizens with developmental disabilities and their families as Council chair. It has been a profoundly meaningful experience for me to witness the impact of the Council's projects on people with disabilities and their families and on our great state.

Mark Ezzell

Council Grant Advances Limited Guardianship in NC

by Deborah Greenblatt

Since 2001, Carolina Legal Assistance has been working under a grant from the North Carolina Council on Developmental Disabilities to make limited guardianship a realistic alternative to full guardianship for people with disabilities in North Carolina.

Limited guardianship addresses areas of strengths for people with developmental disabilities, allowing them to maintain control of some areas of their lives where they don't need a guardian.

North Carolina law had previously permitted limited guardianship, but the law was not crystal clear and the forms used by the Clerks of Court did not make it easy.

During the first year of the grant, pilot sites were established in Mecklenburg, New Hanover, Scotland, Wake and Watauga counties to test forms that were developed to encourage the use of limited guardianship. Much feedback was received and the forms were revised more than once.

Also from 2001 through the present, Carolina Legal Assistance made scores of presentations, including several to the North Carolina General Assembly, urging people to try the pilot forms throughout the state.

In the past two years, there have been exciting developments for limited guardianship in North

Carolina. During the 2003 session of the General Assembly, under the sponsorship of Rep. **Jean Butterfield**, the law was changed to make the option of limited guardianship clearly available to all and to encourage the consideration of limited guardianship by Guardians Ad Litem and Clerks of Court (HB 1123).



Then on July 9, 2004, after a year of work and deliberation, the Forms Committee of the Administrative Office of the Courts (AOC) adopted new forms for all guardianship cases. The AOC consolidated the information from the limited guardianship pilot forms into one new set of forms to be used in all cases involving guardianship.

The Guardianship Capacity Questionnaire will now be available in all 100 counties from the Clerk of Court, and check-off for limited guardianship options will be available on all of the forms for the Petition for Guardianship, Motion to Change Guardianship and Order. Separate Letters for full guardianship and limited guardianship will be available depending on the outcome of the case.

This summer, the NCCDD will release a handbook for the parents of teenagers with disabilities. The handbook describes guardianship options and guides parents through the guardianship process. To request a copy of this guide, contact Beryl Aldeberan at the NCCDD at 919-420-7901 or at Beryl.Aldeberan@ncmail.net.



Where Do You Stand on the Issue of Genetic Research?

by Dawn Douglas

Through the Human Genome Project (HGP), scientists began linking genetics to disabilities by identifying what genetic information is passed from one generation of a family to another. These findings have many ethical, legal, political and social implications.

Results of the HGP offer both hope and concern for people with disabilities and their families. From a hopeful perspective, genetic research provides insight to prevent, treat or ameliorate some disabilities.

However, there are concerns about the HGP results. How will society, insurance companies and employers—to name a few—manage the knowledge of a person's human genome (the full collection of genes in a human being)? There is concern that this knowledge could lead to segregation, discrimination and diminished confidentiality. Elimination of disabilities could also result in loss of potential contributions to society. For example, Temple Grandin has autism. Without the influence of her autism, it is unlikely she would have become one of the country's leading experts on livestock management.

The Beach Center on Families and Disability at the University of Kansas is studying many of these issues. Its researchers are gathering, reporting

and coordinating data on the opinions of people with disabilities and their families. They are looking at:

- The hopes and fears of the disability community about human genetic research and technologies;
- The sources, contexts, timing and potential impacts of these hopes and fears and how they relate to different types of disabilities; and
- What ethical, legal, policy and social responses, education initiatives and healthcare delivery practices can address these expectations and concerns.

The Beach Center is collecting information from relevant literature, in-depth interviews and focus groups. In February, the North Carolina Council on Developmental Disabilities acted as liaison for the Beach Center to organize focus groups in Chapel Hill, Lumberton and Raleigh. Attendees, who were people with various disabilities or parents of children with disabilities, generated insightful and valuable discussion.

For more information about the Beach Center's research project, go to www.beachcenter.org or to learn more about the Human Genome Project, go to www.ornl.gov/sci/techresources/Human_Genome/home.shtml.

PACE Meeting Addresses Special Education Compliance



In November 2004, leaders from Parents' Alliance for Compliance in special Education (PACE) met with Dr. **Troy Justesen**, assistant secretary for the Office of Special Education and Rehabilitative Services, U.S. Department of Education, to share concerns of parents from across the country. This meeting was a continuation of a dialogue between PACE and Justesen held earlier in the year.

PACE is an organization of parents and concerned parties working to address noncompliance of special education law in the nation's public schools. PACE leaders from North Carolina, Illinois, Wisconsin, Florida and New York, as well as **Larry Ringer**, monitoring team leader for the Office of Special Education Programs, U.S. Department of Education, participated in the meeting with Justesen. Ringer's team monitors several states including North Carolina.

The following is a synopsis of some of the concerns and comments shared at this meeting.

NCCDD member **Lawrence Shockey** expressed his struggles as a parent advocating for the needs of his son, **Alec**. Lawrence adopted Alec when he was 22 months old.

“Alec was born three months premature, crack addicted, asthmatic, and profoundly deaf with global developmental delays. By his third birthday,

he was additionally diagnosed with autism and ADHD. It has taken me almost four years of intense advocating to get my son equal access to communication in the classroom. Now I am fighting to get him the services that he needs based on his unique needs due to the autism and ADHD. The school has yet to seriously address these issues.”

Mark and Dona Kay Hannagan (Florida) addressed the management of complaints and accountability:

“Our main concern is accountability. When there is a complaint, it appears that no agency is willing to stand up for the children and take responsibility. Our family has literally been on the brink of bankruptcy for five years due to defending our child's right to FAPE [free and appropriate public education]!”

PACE Board President **Eva Marie Roberts'** (Wisconsin) comments also focused on accountability and compliance monitoring:

“As you [Justesen] reported to the Committee on Government Reform only five months ago, President Bush stated, ‘I am committed to tearing down the remaining barriers to equality that face Americans with disabilities today.’ PACE wants to aide in the process of tearing down those barriers, and it is for this reason I would like to share with you PACE's concerns about an existing barrier surrounding federal and state accountability. That would be the Office of Special Education Programs' (OSEP) procedures and practices for monitoring compliance of the individual states.”

Roberts elaborated on PACE's concerns about the Office of Special Education Programs, U.S. Department of Education's current monitoring practices. These include allowing states to submit

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Educating and Pushing for Change—A Capitol Hill Experience

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Among the many issues presented to policymakers, the hot topics were budget and appropriations. In the midst of the federal government trying to repair the deficit, programs that support persons with developmental disabilities are continuously on the chopping block.

“I just could not get over the feeling that people thought that the only way to fix the budget would be to make cuts in programs that affect a population that needs the most help...that kind of plan reeks of injustice,” said **Rosemary Bernauer**, a Council member also representing Arc of Stanly County at the seminar.

Receiving information regarding federal budget cuts left supporters dismayed yet hoping for a change of action. According to Rosemary, the trip to Capitol Hill was empowering, “emotional, mind boggling and life altering.”

Participation in Disability Policy Seminar 2005 Partnership for Empowerment is just one way the NCCDD shows its support of the Developmental Disabilities Assistance and Bill of Rights Act, which encourages that all persons with developmental disabilities achieve interdependence and inclusion into society. The Act mandates the Council’s implementation of a State Plan involving advocacy support, capacity building and systemic change activities.

PACE Meeting

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self-assessments on their compliance with special education law. The self-assessments are in lieu of on-site monitoring visits from the OSEP. Some states, including North Carolina, have been without an on-site monitoring visit for a decade.

As a result of the November conference, the Office of Special Education Programs, U.S. Department of Education scheduled another meeting between PACE and OSEP representatives. The purpose of the follow-up meeting will be to delve more deeply into the issues surrounding accountability at the state and federal levels.

North Carolina Disability Action Network Focuses on Civic Participation

According to the U.S. Census, there are more than 1.8 million people with disabilities in North Carolina. However, North Carolina has never had a statewide organization, made up by and for people with all kinds of disabilities, whose primary purpose is to involve people with disabilities in the leadership of their communities.

... Until now!

NC DAN is that network. Most importantly, it will be **YOUR** network and it will be made up entirely of local people concerned about disability issues. It will be a way for people with disabilities and grassroots disability organizations to come together to learn about and work to involve the disability community in the life of our larger community.

Local NC DAN chapters will address issues such as voting participation, grassroots organizing techniques, information sharing and public education. NC DAN will also be a “one-stop shop” for local organizations to learn about each other and the fine work other community disability groups are doing.

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Blend! Make a Date with Art

by Dawn Douglas



“Blend” is the word used to embody the vision for Eastside Cultural Garden. Its recent arts-based program meets the organization’s mission of providing a unifying force linking neighborhoods, businesses, groups and individuals and promoting community through creative expression. “Blend! Make a Date with Art,” which opened March 4 at the Hart-Witzen Gallery in Charlotte, represented the unification and celebration of diverse individuals and talents.

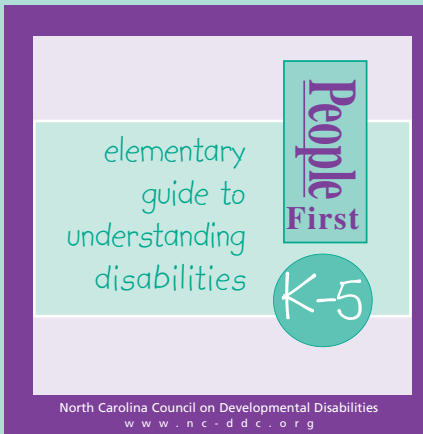
Eastside Cultural Garden, now in the third year of its NCCDD grant, believes that anyone can be an artist by nurturing one’s creative spirit. Attendees at the “Blend” exhibit were treated to short stories, poetry, pictures and paintings as artists of various ages and abilities experienced the feeling of empowerment and accomplishment that comes with sharing one’s work. The positive environment of inclusion and inspiration created distinctive motivation for not only seasoned art fans but also for those seeking to tap into new energies.

“Blend! Make a Date with Art” was one of many participants in Charlotte’s monthly NoDa Gallery Crawl in the North Davidson Arts District, where onlookers are given the opportunity to “crawl” from gallery to gallery viewing the creations of local residents. The diverse presence of attendees, many of whom were featured artists, created a unique and relaxed atmosphere.



North Carolina Council on Developmental Disability grant funding for “Changing the Rules,” a micro-enterprise project, has assisted **Larry Cooper** (above left) start his own coffee business. Larry and **Dawn Douglas** (NCCDD staff) attended the reception at the opening of Eastside Cultural Garden's *Blend! Make a Date with Art*.

Council Releases *People First* for Kids



When you talk about a friend without disabilities, do you describe him as, “That’s Joe and he doesn’t have a disability”? Probably not.

That’s just one of the questions the NCCDD asks in its new *People First K-5*, created to educate children about

disabilities and how to appropriately communicate with and about people with disabilities.

People First K-5 is for kids with or without disabilities, as well as for the adults that work with them. The booklet explains the importance of using people-first language to let people with disabilities know they are accepted and included. It helps children learn language they can use when talking about their own disability or referring to someone else’s disability.

The booklet also includes tips that will make kids more comfortable with each other as they play and go to school together. *People First K-5* provides activities designed to teach children about disability etiquette and to gain a better understanding of what having a disability might be like.

“*People First K-5* is an important step in beginning disability awareness at a young age,” said NCCDD Chair **Mark Ezzell**. “As stated in the introduction, it is important to remember we are all people first. Cherish and celebrate our differences. It’s what makes each of us special.”

NCCDD also produces *People First* for adults, which is now in its sixth revision and also offered in Braille, large print and Spanish.

To order free copies of *People First K-5* or *People First*, contact Beryl Aldeberan at the NCCDD at 919-420-7901 or at Beryl.Aldeberan@ncmail.net.

Medicaid “Buy-in” Coverage Is Ticket to Work

Work is underway to pass legislation in North Carolina that will allow working adults with disabilities to share in the cost of their Medicaid coverage. Rather than losing their Medicaid benefits because they earn too much income, participants would have the option to pay premiums or other cost-sharing charges. According to North Carolina Sen. William Purcell, “This is the right thing to do and it should have been done long ago.”

The Issue

According to a national survey, the number one reason that people with disabilities gave for not going to work was fear of losing their essential medical benefits. Currently, people with disabilities have to limit their wages or risk losing their Medicaid benefits. Existing disabilities cause most to be ineligible for private health insurance plans or plans offered by employers. People with significant disabilities who have some medical improvement may also lose their health care coverage through Medicaid even though they still have ongoing healthcare needs.

The Medicaid Buy-In Program

The Centers for Medicare and Medicaid Services (CMS) awarded the N.C. Division of Vocational Rehabilitation Services (DVRS) in partnership with the N.C. Division of Medical Assistance (DMA) a

grant to develop a Medicaid buy-in program for individuals with disabilities who choose to work. The Blue Ribbon Commission on Medicaid Reform was formed as a result of this grant to make recommendations for revisions to North Carolina's Medicaid program.

The buy-in is a Medicaid program made possible by the federal Ticket To Work Act and Work Incentives Improvement Act of 1999. This Act creates new Medicaid eligibility categories for persons with disabilities who work. Those who meet the disability and financial eligibility requirements would pay an annual fee, premium and/or co-pay to keep their Medicaid health insurance. With a Medicaid buy-in program, every adult with a disability could work to his or her full potential, with all the accompanying personal and state economic benefits, without fear of losing health insurance.

North Carolina Legislation

The North Carolina Blue Ribbon Commission on Medicaid Reform recommended that “the General Assembly expand Medicaid eligibility under the Ticket to Work and Work Incentives Improvement Act of 1999 to persons who are age 16 through 64 who are disabled, but who are working; and Persons who have received Medicaid in the first group, who lose eligibility for that group due to medical improvement, but who retain a severe impairment.”

Sen. William Purcell and Reps. Edd Nye, Jeff Barnhart, Bob England and Beverly Earle are leading a bipartisan effort to enact legislation to provide the Medicaid buy-in program. They introduced Senate Bill 119/House Bill 80, titled Ticket to Work/Medicaid Eligibility. The Healthcare Committee approved this legislation, with revisions, and referred it to the Appropriations Committee. If this legislation is passed into law, it will be called the Health Coverage for Workers with Disabilities Act and could become available as early as January 2007.

Call to Action

It is important for people with disabilities and their families to contact their state legislators to request their support of Senate Bill 119/House Bill 80, Ticket to Work/Medicaid Eligibility. For possibly hundreds of thousands of North Carolinians with disabilities, this Medicaid buy-in program means increased independence and support in achieving goals. For legislator contact information, go to www.ncga.state.nc.us.

- North Carolina's Medicaid buy-in program will allow people with disabilities to go to work and become financially independent without fear of losing their essential medical coverage.
- There will be annual fees, premiums and/or co-payments that will be based on income.
- Thirty-three other states have approved a Medicaid buy-in program that allows individuals with disabilities to go to work without losing their Medicaid.
- The buy-in program, if passed, could become available as early as January 2007. This will allow the Division of Medical Assistance time to implement its new data system and prepare for the program.
- Eligibility for the Medicaid buy-in program includes participants being able to provide evidence of paying applicable Medicare, Social Security, and state and federal income taxes.

This publication is produced by the North Carolina Council on Developmental Disabilities, established by the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 106-402) to promote interdependence, contribution, self-determination, integration and inclusion into the community for citizens with developmental disabilities.

The N.C. Department of Health and Human Services does not discriminate on the basis of race, color, national origin, sex, religion, age or disability in employment or the provision of services.

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This toll-free number is available for people with developmental disabilities and their families.

www.nc-ddc.org

Project Spotlight: Access Dental Care

North Carolina's citizens with developmental disabilities are greatly in need of oral health services.

- Dental providers are often ill-equipped to treat a population that may need creative treatment techniques, and don't have an understanding of unique physical and mental conditions and social work support.
- Caregivers often don't know how to provide home dental care to people with developmental disabilities.
- Medicaid fees do not adequately compensate dentists for their services.



Access Dental Care (ADC), a nonprofit organization based in Greensboro, is addressing these obstacles to good oral health for people with developmental disabilities. Using funds from a NCCDD grant, ADC is identifying the dental needs of people with developmental disabilities, training dentists to care for people with developmental disabilities in their offices, serving as an information clearinghouse on dental services, and

working with the state to change those regulations and reimbursement practices that make it difficult for people with developmental disabilities to access care.

ADC is also providing on-site dental services to approximately 1,500 individuals with developmental disabilities in Guilford, Randolph, Davidson, Forsyth, Stanly, Rowan, Cabarrus and Iredell counties. As part of this care, ADC teaches patients and their caregivers about the importance of regular brushing and flossing and train them in the best way to do this. Services are provided by ADC/Greensboro, ADC/Cabarrus and Baptist Hospital Special Needs Unit.

As part of this project, ADC will identify dentists willing to treat patients with developmental disabilities. ADC will train 300 healthcare providers in three statewide workshops insuring that people with developmental disabilities will have greater access to dental care services.

To determine the dental health needs of people with developmental disabilities, ADC will survey 1,000 people with developmental disabilities. The results will serve as baseline data to measure the effectiveness of future programs. Currently, North Carolina has no data on the oral health needs of this population.

A key component of this project is promoting change in North Carolina's current dental health programs and improving accessibility to dental healthcare services by people with developmental disabilities. ADC will bring dentists, consumers and state officials together as an advisory board to find specific, measurable programs to improve the dental health of people with developmental disabilities.

ADC will also work with North Carolina officials and policymakers to review and update programs that deal with dental care for people with developmental disabilities. Therefore, care can be provided to more individuals and the dentists that can be adequately reimbursed for their work. A statewide plan to create a network of special-care dental providers will also be developed.



ADC's efforts are receiving state and national attention. Several other areas of North Carolina have contacted ADC to discuss bringing dental care to people with developmental disabilities in their regions. The

National Association of Developmental Disability Directors interviewed ADC staff for an article on special-care dentistry in its publication. ADC also represented the NCCDD at the Assistive Technology Conference in Raleigh and the Southern Association of Institutional Dentists Conference in Asheville.

North Carolina Disability Action Network Focuses on Civic Participation

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NC DAN will work closely with local disability groups to offer training and technical assistance that will assist people with disabilities in becoming more involved in civic affairs. Training needs will be determined largely by the recommendations coming from the community forums. Potential topics may include working with media, developing a grassroots campaign and community outreach techniques.

We invite you to become involved in one of the most exciting organizations ever created by and for people with disabilities—The North Carolina Disability Action Network (NC DAN). Would you like to host an NC DAN meeting in your town or region? Contact us at NCAction@nc-ddc.org and indicate that you would like to host or assist in hosting an NC DAN local meeting. Then, NC DAN will provide contacts with other NC DAN members in your area and provide you with the tools and training to host your own local meeting. We will also keep you updated as other groups plan meetings in your area of the state.

Sign up at www.nc-ddc.org for our contact list so we can keep you informed of the latest NC DAN activities and events.

The NC Disability Action Network is a project of the NC Council on Developmental Disabilities. To learn more about the Council, visit its Web site at www.nc-ddc.org.

(NC DAN is a nonpartisan, grassroots citizen action and advocacy project of the NC Council on Developmental Disabilities.)

North Carolina Council on Developmental Disabilities

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Self-Advocates of North Carolina (ASANC)

North Carolina Council on Developmental Disabilities is pleased to welcome our newest neighbors, Association of Self-Advocates of North Carolina (ASANC). ASANC, housed in our office, has a long history of advocating for people with disabilities with NCCDD. For additional information, contact Karen Stallings, executive director, at 919-420-7995, 3801 Lake Boone Trail, Suite 260, Raleigh, NC 27607.

Join the Council and Make a Difference

Are you interested in taking your commitment to improving the lives of people with developmental disabilities and their families to the next level? Do you want to provide leadership in an organization that identifies and funds leading-edge initiatives that effect critical systems change and directly affect people with disabilities?

The North Carolina Council on Developmental Disabilities invites qualified candidates to apply for Council membership. The Council is comprised of 34 members appointed by the governor. Of these Council members, 60 percent are people with developmental disabilities or family members of people with developmental disabilities. Council members serve four-year terms.

The NCCDD annually receives approximately \$1.973 million in federal funds through the N.C. Department of Health and Human Services from the

U.S. Administration on Developmental Disabilities. The Council members decide how those funds will be used based on a five-year State Plan.

If interested, please visit the NCCDD Web site at www.nc-ddc.org. Click on Membership Application for additional information and to download an application. You may also call 919-420-7901 voice/TDD or 1-800-357-6916.

