

GRASSROOTS  
EXPERIENCES WITH  
GOVERNMENT  
PROGRAMS AND  
DISABILITY POLICY

Proceedings from a Public Hearing in  
New Orleans, Louisiana

National Council on Disability

# October 1, 1998

**National Council on Disability**

**Grassroots Experiences with Government Programs and Disability Policy: Proceedings from a Public Hearing in New Orleans, Louisiana**

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The views contained in this report do not necessarily represent those of the Administration, as this document has not been subjected to the A-19 Executive Branch review process.

Please Note: It was beyond the scope of this project for NCD to independently research and confirm statements made by witnesses in our hearing. The statements and recommendations are included as they were received at the hearing.

## LETTER OF TRANSMITTAL

October 1, 1998

The President  
The White House  
Washington, DC 20500

Dear Mr. President:

On behalf of the National Council on Disability (NCD), I am pleased to submit a report entitled *Grassroots Experiences with Government Programs and Disability Policy: Proceedings from a Public Hearing in New Orleans, Louisiana*.

The report is based on a public hearing NCD conducted to learn about issues facing families of children and youth with disabilities from minority and rural communities in Louisiana. Recognizing society's general neglect of the needs of minorities, NCD has targeted children and youth with disabilities from minority and rural communities as one of its policy priorities.

Several recommendations for action by local, state, and national policymakers emerged from the hearing. Although this report attempts to capture the substance of the compelling testimony, it is beyond the scope of this report for NCD independently to research or verify what was said at the hearing. NCD elected to highlight the voices from one state as a vehicle to draw lessons for public policy and its impact at the local level.

NCD stands ready to work with you and stakeholders outside the government to see that the needs of all Americans with disabilities and their families are met.

Sincerely,

Marca Bristo  
Chairperson



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# CONGRESSIONAL MANDATE OF THE NATIONAL COUNCIL ON DISABILITY

## Overview and Purpose

NCD is an independent federal agency led by 15 members appointed by the President of the United States and confirmed by the U.S. Senate.

The overall purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

## Specific Duties

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act; as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities, in order to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.
- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local levels, and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on individuals with disabilities, access to health care, and policies that operate as disincentives for individuals to seek and retain employment.

- Making recommendations to the President, Congress, the Secretary of Education, the Director of the National Institute on Disability and Rehabilitation Research, and other officials of federal agencies, respecting ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.
- Providing Congress, on a continuing basis, advice, recommendations, legislative proposals, and any additional information that NCD or Congress deems appropriate.
- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.).
- Advising the President, Congress, the Commissioner of the Rehabilitation Services Administration, the Assistant Secretary for Special Education and Rehabilitative Services within the Department of Education, and the Director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.
- Providing advice to the Commissioner with respect to the policies and conduct of the Rehabilitation Services Administration.
- Making recommendations to the Director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting persons with disabilities.
- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this Council for legislative and administrative changes to ensure that such recommendations are consistent with the purposes of NCD to promote the full integration, independence, and productivity of individuals with disabilities.
- Preparing and submitting to the President and Congress an annual report titled *National Disability Policy: A Progress Report*.

## **International**

In 1995, NCD was designated by the Department of State to be the official contact point with the U.S. government for disability issues. Specifically, NCD interacts with the special rapporteur of United Nations Commission for Social Development on disability matters.

## **Consumers Served and Current Activities**

While many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, status as a veteran, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of persons with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, it was NCD that originally proposed what eventually became the Americans with Disabilities Act (ADA). NCD's present list of key issues includes improving personal assistance services, promoting health care reform, including students with disabilities in high-quality programs in typical neighborhood schools, promoting equal employment and community housing opportunities, monitoring the implementation of ADA, improving assistive technology, and ensuring that persons with disabilities who are members of minority groups fully participate in society.

## **Statutory History**

NCD was initially established in 1978 as an advisory board within the Department of Education (Public Law 95-602). The Rehabilitation Act Amendments of 1984 (Public Law 98-221) transformed NCD into an independent agency.



## PREFACE

The National Council on Disability (NCD) is an independent federal agency that makes recommendations to the President and Congress on disability policy. Recognizing society's general neglect of the needs of minorities, NCD has targeted children and youth with disabilities from minority and rural communities as one of its policy priorities.

As a follow-up to findings in NCD's 1996 report *Achieving Independence: The Challenge for the 21<sup>st</sup> Century* that key information related to the rights and services available to people with disabilities is not reaching a large segment of the American population, especially people from minority and rural communities, NCD conducted a roundtable discussion in Atlanta to address these critical issues. At the NCD roundtable, several people called attention to the need for federal enforcement and technical assistance to focus resources and initiatives on educating people in minority communities about the requirements of the Americans with Disabilities Act (ADA) and other federal disability civil rights statutes and how to bring claims under these laws.

As a follow-up to the Atlanta meeting, NCD conducted a hearing on the issues affecting children and youth with disabilities from minority and rural communities in Louisiana on January 26, 1998, at the Hilton Riverside Hotel in New Orleans. Louisiana was selected based on its National Composite Rank in the Annie E. Casey Foundation 1997 *KIDS COUNT Data Book*, which provides policymakers and citizens with benchmarks of child well-being. Although Louisiana ranked last out of 50 states, NCD believes that it would have received similar testimony from witnesses in other states. The *KIDS COUNT Data Book*—a national and state-by-state effort to track the status of children in the United States—uses the best available data to measure the educational, social, economic, and physical well-being of children.

In preparation for the hearing, NCD contacted local advocates, people working to improve the lives of children and youth in Louisiana, and staff members of the Office of Special Education Programs, U.S. Department of Education. Hughey Walker, chair of NCD's Subcommittee on Minority Issues, presided at the hearing and expressed NCD's concerns related to education and disability issues, juvenile justice issues, and youth with disabilities. Lilliam

Rangel-Diaz, a member of the Subcommittee on Minority Issues and co-chair of NCD's Subcommittee on Children and Youth, gave a brief overview of NCD and its mission. She also encouraged participants to openly share their experiences.

Several recommendations for action on the part of local, state, and national policymakers emerged from the hearing. This report attempts to capture the substance of the compelling testimony; it was prepared with the valuable assistance of Carol Wilson, one of the parents who testified and helped to organize the hearing. It is beyond the scope of this report for NCD to independently research or modify what was said at the hearing. We have organized what we heard in a manner that we hope will be useful to policymakers at the federal, state, and local levels. We begin with the recommendations we received. They include the following:

### **Education and Vocational Rehabilitation**

- School boards need to make special education funding and staffing a priority and establish a separate budget for the dollars allocated for special education.
- School boards should take an honest look at the evaluation process and technology access and improve the coordination of those services.
- It is incumbent on school boards to devise and enforce policies that will encourage more students with disabilities to stay in school and ensure that every child who is eligible to get a high school diploma has the opportunity to do so. Funding select schools while ignoring other districts and closing enrollment at select schools are barriers that need to be addressed.
- Family support and advocacy programs of diverse cultural backgrounds should be encouraged and supported whenever possible. Strong partnerships among student self-advocates, parents, and the schools will build strong schools and promote community involvement, which has been shown to improve school performance.
- At the state level, funding should be increased for special education, teacher salaries, and to hire competent certified special education teachers.

- Schools should be held accountable for following state and federal guidelines and correcting deficiencies.
- The state Department of Education should increase parent/school partnerships and move away from collaboration with a select few to collaboration with all families. Public hearings and conferences should be open and widely advertised in places where all cultural segments of the population would be likely to receive the information.
- Training for families should encompass all disabilities and cultures and should be widely available. Families of diverse cultural backgrounds and disability experiences should be actively recruited and allowed to serve in leadership positions. Training should include Section 504 and civil rights training and be more effective in addressing the complaint and documentation process.
- The School-to-Work program should cooperate with the Louisiana Statewide Transition Project to provide a better array of services with available funding and to avoid overlapping efforts in some areas.
- Increase outreach to rural areas in following the provisions of Act 417 for universal screening of newborns for hearing impairment.
- Advocates would like to see a greater federal involvement with accountability measures for federally funded projects. Input from a wide range of consumers who are the intended beneficiaries of these projects would give a more accurate picture of how effective the projects are.
- Congress should not pass any amendment that has potential to weaken the Individuals with Disabilities Education Act (IDEA). Testimony in this report indicates a lack of understanding regarding students with disabilities, as well as continuing attitudinal barriers of fear and prejudice, both in schools and among the general public. Allowing school boards to expand disciplinary practices would create more barriers to students with disabilities receiving a free and appropriate public education.
- Incorporate specific language into child care initiatives that will provide access to competent care for children with disabilities.

- Work toward an improvement in the communication between the Department of Special Education and the Office of Rehabilitation.
- Mandate extensive consumer and family involvement in all phases of decision-making processes.
- Reauthorize the Technology-related Assistance for Individuals with Disabilities Act (Tech Act).
- Improve the access of elementary and secondary children to Section 504 services and ensure that all parents receive training on their rights and responsibilities with regard to Section 504.

### **Juvenile Justice**

- Local, state, and federal officials should collaborate and make it a priority to eradicate abuse and to protect the safety and civil rights of those in juvenile justice facilities.
- Forge community partnerships that will address the problems already known to increase juvenile delinquency, such as lack of access to mental health treatment services and to after-school child care.
- Review ways to address the economic structure in rural communities to eliminate prisons and detention centers as engines of economic opportunity.
- Plan and promote a campaign to educate and inform the general public and policymakers about the realities of juveniles with disabilities, particularly mental health problems.
- By providing access to a full range of treatment options, eliminate the necessity for families of children with a mental health disability to declare their child ungovernable in order to have access to intensive residential options.
- Strongly resist attempts to pass state and federal legislation in the name of fear or convenience that will weaken the protection of juveniles with disabilities in the juvenile justice system.
- Improve access to education and health care in juvenile justice facilities.
- Make effective rehabilitation the rule and not the exception.



## Access to Medical Services

- Enact legislation that provides for consumer protections and considers the needs of people with chronic health conditions. Mandate an advisory council to provide quality assurance controls. This council should include consumers and families representative of the major disability categories (i.e., developmental disability, chronic illness, injury, and brain disorders or mental illness).
- Ensure that the Office for Civil Rights in the Departments of Health and Hospitals in all federal regions have funding and staff to investigate complaints of violations.
- Establish a commission of local, state, and federal policymakers, consumer/family advocates, and community leaders to explore options for financial management of chronic health conditions. Enact legislation that will ensure that insurance companies in America will provide benefits for managing these conditions.
- Enact federal comprehensive mental health parity legislation that will provide protections for employers and employees so that the discrimination against persons with psychiatric disabilities can end and the government will not be forced to pick up the costs for the majority of these people because of a lack of adequate private insurance coverage.
- Mandate genetic screening of newborns to determine chromosomal anomalies not readily apparent and ensure that insurance companies can not use such results to discriminate against people who have these conditions. Many of these anomalies have been documented to be costly in terms of quality of life and the treatment for their manifestations when they remain undiagnosed and no interventions are provided. Early screening can lead to early intervention services to improve outcomes, treat the anomaly, and enhance the general quality of life.
- Mandate the Tax Equity and Fiscal Responsibility Act as a formal part of Medicaid instead of allowing it to continue as a state option.
- Proactively eliminate and punish fraud and abuse of the Medicaid system, particularly by providers. Examine the disproportionate share hospital funding and the profit schemes in

Louisiana that were not direct violations of the law and thus led to losses that could not be recouped. Devise a method whereby personal profiteering can be eliminated.

- Fund and support total wraparound services for children and youth with mental disabilities (e.g., serious emotional disturbances). Tailor the system to meet the needs of the consumer instead of requiring the consumer to meet the needs of the system. Provide a full range of treatment options and multidisciplinary cooperation that is consumer driven and directed.
- Solicit consumer and family involvement in all stages of health care provision. Foster and actively promote family and consumer involvement and pay these people for their services as any professional would be compensated.
- Fund consumer- and family-driven health advocacy groups to do training across the country on Medicaid, health insurance, family/professional collaboration, and consumer rights and responsibilities.
- When conducting federal investigations of state departments of health, mental health, developmental disabilities, and Medicaid, actively solicit input from consumers and families from a broad spectrum of cultures, geographic regions, and disabilities. Use family- and consumer-driven health advocacy groups to locate these individuals. Fund those groups to train and compensate consumers and families for surveying other consumers and families to obtain more accurate data.
- Louisiana state officials and the legislature should make it a priority to fund the developmental disability waiver slots and search for ways to move the more than 10,000 people off the waiting lists. Reports of preventable deaths of consumers because of a lack of services while on a waiting list demand that the system be closely examined to find ways to prevent this in the future. Investigate a voucher system that would allow the limited dollars to provide services for more people.
- Louisiana Medicaid and the legislature should raise the provider reimbursement rates at least to the Southern Conference standard. Also examine ways to make the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) rates equitable when compared with the developmental disability waiver rates.

- Enact minimum training requirements for those who provide direct care and support services. In particular, develop a training, licensing, and accreditation system for paraprofessionals. At present, the psychiatric technicians who work in the state hospitals are required to have only a general equivalency degree (GED) and the physical ability to put someone in restraints. Reports of abuse and violations of civil rights are grave concerns and need to be addressed. Make sure all training addresses diversity of race, disability, and creed. Invite consumers and families to participate in such training and compensate them, to ensure that service providers hear the message that services should be provided in the most respectful, least intrusive way possible and that all services should be consumer driven and directed.
- Improve coordination of care across all systems. Promote multidisciplinary team approaches that are consumer driven and directed.
- Overhaul the current psychiatric hospital system, in which youth of all diagnoses are put together and often participate in the same treatment plans or group therapies. Just as one would not use the same treatment for a patient with a heart condition and a patient with cancer, it does not make sense to use the same treatment for a youth with bipolar disorder or schizophrenia and a youth suffering from a behavior disorder or emotional disturbances due to severe and repeated abuse. Treatment for mental health disabilities is more than medication and should include a total individualized recovery model.
- Revitalize the current psychiatric hospital system to allow for the safety of the patients and staff while creating a more family-centered approach to care. Locking children and youth away from loving families and friends at such a frightening and difficult time is not in their best emotional interests.
- Make it illegal for states to require families to relinquish custody of their children to obtain intensive mental health services and treatments for them.
- Closely examine the funding streams and find ways to eliminate cost shifting between the state and federal governments.
- Examine ways to improve the delivery and quality of services to rural areas. Investigate ways to attract providers to these areas.

## **Economic Self-Sufficiency/ Independent Living**

- For those who meet the Supplemental Security Income (SSI) definition of disability, separate the requirement of a cash SSI payment from access to Medicaid.
- Encourage independent living and shift funding from costly institutional care to community-based services.
- Make a concentrated effort to let employers know that the Americans with Disabilities Act and the Family and Medical Leave Act do protect the rights of those with mental health disabilities.
- Increase the federal minimum wage.
- Promote and fund programs such as Partners in Policymaking.
- Increase funding for Independent Living Centers.

## **Family/Individual Support**

- Louisiana should invest itself in the funding and success of Act 378, the Family and Community Support Services provision.
- Launch a national campaign to improve the delivery of community and family/consumer support services across the country.
- Adequately fund providers of community and family support who meet strict requirements that will prevent abuse and fraud.
- All support should be consumer/family driven and directed as well as culturally competent and respectful.
- Investigate ways to provide skills training and medical services to families in which single parents and others must leave the workforce to care for the child or youth with a disability.
- Solicit input on quality assurance from families and consumers. Involve families and consumers in all stages of support, from planning to implementation.

## **Community Participation**

- Encourage community summits to discuss the issues and create innovative solutions. Include persons with disabilities and ask them what their issues and concerns are.
- Use the media to portray the truth about persons with disabilities and to lessen the stigma and attitudinal barriers.
- Foster collaboration and partnerships of government, service providers, businesses, and other stakeholders in the community.
- Hold leadership training for youth with disabilities and provide them with mentors and opportunities to learn to be self-advocates.



## **INTRODUCTION**

Hughey Walker, chair of the National Council on Disability's (NCD) Subcommittee on Minority Issues, opened the hearing by stating that NCD was particularly interested in hearing about the issues affecting Louisiana youth with disabilities and their families. He expressed the hope that NCD would be able to gather information on children and youth from minority backgrounds and rural communities in Louisiana that would help NCD in its work. He discussed NCD's long-standing commitment to minority issues.

Mr. Walker informed those present that in preparation for the hearing, NCD had contacted local advocates and people working to improve the lives of children and youth in Louisiana, as well as staff in the Office of Special Education Programs at the U.S. Department of Education in Washington, D.C. He expressed the concerns of NCD as related to education and disability issues, juvenile justice issues, and youth with disabilities.

Lilliam Rangel-Diaz, a member of the Subcommittee on Minority Issues and co-chair of the NCD Subcommittee on Children and Youth, gave a brief overview of NCD and its mission. She encouraged those present to openly share their experiences.





## **EDUCATION**

NCD expressed concerns about surrounding education for those with disabilities in Louisiana that were identified after federal monitoring by the U.S. Department of Education. Problems include the following:

- Special transition programs are not fully in place, especially with students moving from school to work for higher education;
- Invitations to transition meetings often lack necessary information;
- Attendance at transition meetings is inadequate;
- Written and prime notice to parents and the required content of the notice are inadequate;
- Attendance at Individualized Education Plan (IEP) meetings, especially by supervisors who could approve or disapprove the expenditure of funds, is poor;
- The state fails to make individual determination of services and placement; and
- The state fails to force correction of these deficiencies.

The hearing testimony confirmed these concerns as well as others. Families, persons with disabilities, officials, and advocates spoke openly of their challenges and successes as well as what is and is not working within the systems.

### **High School Completion**

Witnesses at the hearing expressed concerns that while the national average for youth with disabilities to complete high school is about 38 percent, approximately 54 percent of Louisiana youth do not complete high school. In Louisiana, only 15 percent of all children with disabilities will receive a high school diploma, and 60 percent of youth with serious emotional disturbances drop out of school between grades 9 and 12. Various reasons were given for this. According to Mary Shanks, a representative for the Advocacy Center for the Elderly and Disabled (ACED), Louisiana's federal protection and advocacy program:

In recent years, there has been a backlash against violence in the schools, which has resulted in more Zero Tolerance Programs, which are used to prevent students with disabilities from receiving an education.... Often the damage caused by lengthy removals cannot be undone. The vast majority of youth with disabilities in the state drop out of school before earning a diploma or certificate. The clear message they continue to receive from the school system is that they are not wanted or welcome if they are unable to easily fit into the large middle school or senior high school settings. These problems have been compounded by a lack of specificity in the federal and state law, which have permitted local school systems to impose discipline in a variety of inappropriate ways.

### **Financial/Legal Issues with the Individuals with Disabilities Education Act (IDEA)**

The Department of Education's Office of Civil Rights has investigated and found an overrepresentation of minority students in special education, particularly in E/BD programs, throughout Louisiana. Students from minority groups who exhibit behavior problems are placed in special education first, before other interventions and modifications are explored. For many minority students, the environmental conditions that cause delays are not addressed adequately through early intervention. The issue is currently being addressed through the Office of Civil Rights. Ms. Shanks touched on these concerns in her testimony:

...IDEA was amended to provide additional specific directions to school systems about the procedures they must follow if they discipline students with disabilities.... Unfortunately, in this state, the law has not been implemented by most school systems, who have been led to believe that they can wait a year or more until detailed regulations are finalized before they must begin protecting the rights of students with disabilities. The Advocacy Center has made it a priority to deliver the message loud and clear to all school systems that they must follow the law this year and they cannot continue to remove students with disabilities from school for extended periods of time. This issue affects thousands of students already in special education, as well as those that should qualify of being suspected of having these disabilities. Particularly in large urban districts, many such students are ignored and are never referred for services they need in order to learn. Not surprisingly, this contributes to behavior problems, which are then solved by expelling the students or encouraging them to drop out, thus depriving them of education opportunities that will prepare them for life.

The schools and parents expressed concerns about the safety of children designated medically fragile as well as for the safety of the other children. A student who is ventilator-dependent must have oxygen at school and in transport, which entails hazards that must be guarded against. The funding attached to IDEA is not sufficient to protect children against these safety hazards. Although schools have received more funding this year, additional money is needed to ensure the provision of services that students need. The number of medically fragile students who are medically fragile who were once on homebound or hospital instruction is increasing. Dr. Rosalynne B. Dennis stated:

If you could just get through all of the medical needs, to ensure that they're safe at school, and that the personnel who work with them are fully trained. And that takes a lot more than \$400 and whatever it is per child.

Federal money attached to IDEA and the slightly more than \$2,000 per child from the State Department of Education through minimum foundation funding are not enough to address the special health needs of children in the schools. The funds go into the general fund of each district's budget and provide the teacher, the classroom, lights, maintenance, and limited paraprofessional services. The funds will not stretch to cover child-specific items for those with disabilities. Officials in special education do not receive the funds directly nor do they have much input as to how the funds are spent. Recent deep budget cuts in many districts have hurt special education more than any other area of education.

The school systems were reported to be doing only the minimum required by the Federal Government. With no federal mandate on timelines to provide specific evaluations, services, or assistive technology, services are put off until families threaten lawsuits. One child was reported to have been in the education system for two years with his disability, and yet the parents are still struggling to have him evaluated for an augmentative communication device. A private agency across the state from the family's rural home will do an evaluation for \$400. The agency told the family that if the school board would pay for it, the cost would be \$250. The school board delays

the evaluation process with, “We don’t have the staff. We have a long waiting list of children needing to be evaluated.” For many families, the system is not working well.

### **Early Identification and Intervention**

Research has shown that when children with challenges are identified in the early years and provided with intervention services, there is a decrease in disabling factors that can hinder school performance. More children are living in poverty in Louisiana than in any other state, according to the *Louisiana Kids Count* report prepared by Agenda for Children in conjunction with the Annie E. Casey Foundation. Many of these children are not being identified until they enter school, and many live in rural areas and in populations representative of the ethnic minorities that comprise 30 percent of the state’s population and are predominantly African American, Asian American, Hispanic American, and Native American. Even in cases of early identification, families often have limited or no access to intervention services.

Child Net is the early intervention program in Louisiana for the birth-to-three-year-old population. The schools currently do not provide daily instructional services for infants and toddlers, but they do assessments in accordance with the state’s Child Net regulations. The children are evaluated, then the family receives an infant/family service plan that follows them to various community agencies and nurseries that provide those services. Children with obvious disabilities, such as developmental disabilities and intense medical needs, are generally identified early and connected to Child Net. Infants and toddlers with less obvious disabilities are not as easily identified. Families are not always aware of the programs, and often, particularly in rural areas, there is a lack of service providers and a growing lack of assistive technology.

Louisiana State Senator Paulette Irons mentioned a member of her staff who has a child with a hearing impairment. Senator Irons was candid enough to say that her staff member had the weight of a state senate office behind her to help her locate services and early interventions for her child. Now, more and more children with hearing impairments are being identified and

referred to services sooner. Act 417, the Early Identification Act, is a new Louisiana law that provides for the use of new technology for universal screening of children's hearing at birth, rather than waiting to discover the hearing impairments when the children have not begun to speak by age two. Although the statewide program promotes universal screening in the metropolitan areas, some of the rural hospitals are not identifying infants with a hearing impairment as quickly because they still do a paper screening before the hearing test.

There are many parish education programs for children whose hearing impairment has been identified. Specialists go into the parishes to work with the early intervention teachers and provide resources. Sometimes the specialist is the main teacher; in metropolitan areas, the specialist is a resource in a larger program. Because hearing impairment is a low-incidence disability, in rural areas it is difficult to gather enough students to make a class and find a certified or qualified teacher. Another problem for minority groups and in those rural areas is finding culturally competent interpreters. According to Juliette Haynes of the Parent/Pupil Program of the Louisiana School for the Deaf,

To have a true language accessibility and stimulation for the mainstream—I'm talking about in the cafeteria, performances, recess, all that sort of thing—to have a true language model for these people, you need interpreters.

Sandra Dodgins Barney, an audience member and single adoptive/foster parent of children with disabilities, stressed the importance of specific language being written into the new child care initiative for children with disabilities. She expressed the opinion that family day care homes should have resources available to them to facilitate the inclusion of children with special needs:

Creative financing—allowing funding from multiple sources and prorating the cost among several children—could assist in more children being included in family day homes. Standards need to be revised that would ensure that children in family day care would have the opportunity to develop to their fullest extent. That's back to what I

mentioned earlier about kids in poverty, kids who are in environmentally delaying situations. They're not developing appropriately, so we end up with them in special ed.

## **Transition Planning**

After early intervention at the infant and toddler level and by the student's third birthday, children are transitioned into preschool programs. Louisiana then provides educational services for all students with disabilities, ages 3 through 21. If a student turns 21 after the first day of school, services continue through the 22 birthday. Self esteem issues can be a major factor in students' dropping out of school, as few wish to stay in school years longer than their same-age peers. Students with disabilities are often frustrated by negative social experiences and a lack of high school options, so they move into the adult world ill-prepared because of deficits in transition planning.

The Louisiana Statewide Transition Project (LSTP) is a five-year project to address the particular needs of persons with disabilities in transition from youth to adulthood and to seek ways to remedy problems. The programs for persons with developmental disabilities have improved over the years as a result of major advocacy on the part of those affected, but the need for much work is needed for persons with other disabilities. Forging a partnership between LSTP and the federal School-to-Work program has been a challenge in Louisiana. Dr. Dennis mentioned the program and voiced the common misconception in the state that School-to-Work is basically a regular education program. Advocates experience great difficulty in getting across the School-to-Work message that "all means all."

In Louisiana, some special education teachers are unaware that it is a federal mandate for a transition plan to be in place for all youth ages 14 or older who are in special education. Teachers sometimes tell parents who ask for a transition plan for their students with a special education classification and IEP that the plan is done only for students in an alternative program and not those in specially designed regular instruction. Transition plans are often sketchy and do not adequately address all life areas.

The state has been exploring implementation of a self-advocacy program to prepare students in special education to make their own decisions and take responsibility for the direction of their lives. Some parents expressed concerns about this program being presented through the schools without enough discussion, involvement, and collaboration between families and the education system to effectively implement the project with the total support of families. Too many questions now exist in families' minds that have not been answered satisfactorily, particularly given that the schools are not even accomplishing the basics.

At the secondary level, community-based education programs, such as the Alternate Lifeskills Program (ALP), exist to provide students with functional living skills. Many students are assigned worksites where they can be trained for employment. Before leaving school, the students obtain paid employment and continue in that employment. The community is an excellent resource in providing work locations and job training sites for secondary students.

While ALP works very well for those with moderate to severe developmental disabilities, it is too often the only choice available for students with certain disabilities who would require intensive modifications and supports to earn a high school diploma. The program is weak on academics and does not provide a high school diploma or training to prepare to take the General Equivalency Degree (GED) examination. Although the ALP was intended only for students incapable of receiving a high school diploma or GED, academically capable students are placed in the program because of problems associated with the lack of certified personnel or the unwillingness of the regular education classroom teachers to work with these students.

**(Note:** In March 1998, two months after this hearing, special information meetings were held throughout the state by the Louisiana Department of Education Division of Special Populations. The meetings centered on the IDEA changes were to go into effect in July 1998 and included the information that there would be no more diploma and certificate tracks in special education for students with the cognitive abilities to obtain a diploma or GED training. Only children with the most severe developmental disabilities will receive a certificate. All other

students, regardless of disabilities or accommodations needed, will receive equal opportunity to obtain a high school diploma. Officials have assured parents of children with E/BD and other classifications that their children, in accordance with federal mandates, will receive appropriate modifications and interventions. The new IEP form each child must have has an entire page devoted to modifications and accommodations. Although they see this as a positive step, parents and advocates will be keeping their eyes and ears open to ensure that the law is carried out in schools across the state, knowing there is often a vast difference between what should be done and what actually is done.)

Earlene Roth, a member of New Orleans Mayor Marc Morial's advisory board, expressed concerns about high numbers of IEPs in which the students are not working on a diploma. She asked Dr. Dennis why the only jobs were menial positions and no mention was made of young people training to be doctors or lawyers. Schools did not accept the responsibility to provide work experiences for those capable of attaining professional employment because professionals with disabilities can provide this sort of mentoring on their own, and the feeling is that the most seriously disabled, those who are unable to receive this type of professional training, should receive the limited services available. Dr. Dennis and Senator Irons stated their position that the community must take the responsibility to make up for the deficits found in schools and must begin to provide positive role models for the youth. Members of NCD reminded the officials that although these are worthwhile goals, they do not negate the responsibilities of the state to these children and youth to provide a free and appropriate public education and appropriate rehabilitative services.

### **Section 504 Accommodations**

If students meet the criteria for exceptionality under Louisiana Bulletin 1508, the special Education Department will provide services for them. Exceptionality under Bulletin 1508 is linked to a student's intelligence quotient (IQ). Children who have severe cognitive impairments and severe speech and language delays, physical delays, and occupational delays, and who would



benefit from speech, physical, and occupational therapies are denied those services under Bulletin 1508 because their eligibility for services is tied to their IQ. This contributes to many students' being denied access to support services that could enhance their lives, as it is rarely made known to families that these services could be covered under a 504 Accommodation Plan. Students with disabilities that require modification but do not meet Bulletin 1508 criteria, such as attention deficit disorder (ADD) or certain learning disabilities, can receive services under Section 504 from another department not always current in the provisions under 504 for students below college level, if the parents are aware of their legal rights and how to obtain them. Students with ADD and other 504 needs are not being adequately served, and few parents are aware of how Section 504 of the Vocational Rehabilitation Act can be used to gain needed support services.

### **Parent Training and Information Project**

A member of NCD asked participants if the family training and information project, called Families Helping Families (FHF) in Louisiana, offered parents training on how to file complaints with the Louisiana Department of Education and the Office of Civil Rights to obtain legal rights and, if so, how many complaints had been filed or resolved. Participants responded that instructions given to parents were mainly to make phone calls to the Louisiana Department of Special Education and to document them. No training was provided on how to write letters to these offices or on the rights afforded through the law.

Problems with the complaint process included the reluctance of families to follow through because of the fear of exposing their children to vulnerability while in the care of school personnel. Reported incidents of children being subjected to punitive practices at school when parents have taken action concern families greatly. This promotes silence because there is a lack of comprehensive training in many areas on how to address complaints to the Office of Civil Rights about possible retaliation or other civil liberty issues. It is highly unlikely that enough complaints are getting to the Louisiana Department of Education, and it is very probable that

even fewer are being received by the federal Office of Civil Rights because of the prevailing misconception that the Office of Civil Rights deals only with cultural minority issues.

When asked by NCD whether local PTIs had experienced difficulty with contacts with federal efforts to train parents on the new provisions of IDEA, participants responded that parents were being given the U.S. Department of Education training packets. Jane Baker, the FHF parent trainer on the panel, never clearly answered regarding the amount of local contact with federal training for families and she said had not personally attended or conducted such training. She further reported that the understanding of FHF was that the training was not that different than what they had been doing and was “merely updating the law.”

Many people expressed concerns that in some regions FHF was not being as responsive as it should be to minority children, children from low-income families, or children with specific disabilities such as E/BD. Concerns included that those in the administrative positions of FHF are not representative of cultural minorities, that salaries at the administrative level are very high compared with the services available, that parents truly representative of youth with E/BD are not on staff at FHF, that parents working there do not always have an adequate grasp of the needs of families from culturally diverse backgrounds or of those coping with a child with E/BD, that many resource centers are not in easily accessible locations, and that some centers do not keep sufficient hours to assist families.

Families who had worked for FHF expressed appreciation for the information they had received that they would not have had access to if they had not been on the FHF staff, but no explanation was given as to why such information was not readily available to other families. The Louisiana State Planning Council for Developmental Disabilities—along with other state agencies such as Children’s Special Health Services (CSHS) and the Office of Mental Health Children’s Services—partially funds FHF. Some families were grateful that the Planning Council quickly reimbursed (through FHF) individuals and families representative of those with

developmental disabilities for their time and expenses devoted to training and were grateful for the tremendous assistance this population receives from FHF.

## **Tech Act Project**

Members of NCD asked if certain federal programs, particularly the Tech Act project, were helpful at the grassroots level as many participants testified to the difficulty of obtaining certain needed devices such as augmentative communication aids. The federally funded Tech Act project in Louisiana is known as Louisiana Assistive Technology Access Network (LATAN) and has a representative in each region of the state who can be accessed through the local FHF. LATAN is an awareness program that tells people where information can be accessed through other organizations. How to fund the technology is often not clear, and when school systems purchase the devices, they may be reluctant to send them home or may have no one trained in how to use the technology.

Although it is a challenge for projects such as LATAN to be consumer driven, in Louisiana, LATAN chose to implement an option under the Tech Act to become an independent, nonprofit corporation with an all-consumer board of directors. According to Guy Leaf, a parent and a person with a disability,

We're one of only two in the United States that has done that. It's helped us to really understand at the grassroots the needs of consumers: what they need, what they want, and not just systems change, which occurs so, so slowly, but direct, physical, tangible relief for their immediate needs.

Mr. Leaf urged NCD support of the reauthorization of the Tech Act as the 10-year mandate is about to expire. Emphasizing the importance of the Act, he spoke in terms of cultural diversity in Louisiana.

I would just like to answer an earlier question that was asked about cultural diversity here in Louisiana, and particularly, how our Tech Act approaches that. There is probably no state in the union that has such great cultural and geographic diversity as Louisiana. That's one of the reasons why it's nice to visit here. We have to try and preserve our cultural diversity. My son and I are descended from the French settlers who settled New Orleans, the French Creoles. And the Canadian refugees who came from Acadia, and settled the Acadian part of southwest Louisiana. We're very proud of that heritage. We wouldn't want to change it. But, in terms of cultural outreach, it creates great problems, particularly for projects like the Tech Act Project.... We do try to remember the need to be culturally competent, to speak all the languages of our various cultural diversity populations.

## VOCATIONAL REHABILITATION

Chanise Dennis, a graduate student preparing to pursue a career in rehabilitative services and a young woman with renal disease, expressed appreciation for the opportunities that the Vocational Rehabilitation Act had afforded her in being able to attend school. When asked about his experiences with vocational rehabilitation services, Rodney Senigaur, a college student with paraplegia, replied that his problems consisted of being considered a member of his parents' household and under their income. As a result, he was not eligible for various services when the evaluators did an in-home assessment. In Louisiana, the money does not meet the need for vocational rehabilitation; therefore, only those with the most serious disabilities and greatest economic need qualify for services easily. Although he did receive vocational rehabilitation services eventually, the only funding Mr. Senigaur received was for his undergraduate schooling and some for graduate school. No support services were provided. When asked how his disability had affected his college career, Mr. Senigaur replied:

Well, since I was injured in college, when I was able-bodied in college, you know, as teenagers do, we live a carefree lifestyle. I was doing quite well in school, but yet I was enjoying the other benefits of life. And since I've been disabled, I do appreciate everything now, and I do put everything in perspective. I guess the main thing that I could stress would be that, in spite of your disability, you can still overcome these various barriers. It does really make you persevere. And, you can be as resilient as you want to be. Having the support factors in your life—whether it be family, friends, loved ones, having a spiritual foundation—you can accomplish any goals that you set for yourself.

Mr. Senigaur expressed concern about the speed at which accommodations are provided to students with disabilities. He felt the time it takes the administration to complete the process and develop the proper equipment to help is too lengthy. Another student added that various institutions should be made accountable for not being up to the standards:

I've known times when I needed a computer, or some other type of device to help me within my class, or a tape recorder, or something, and by the time I got it, the semester

was almost over. And this put me at a disadvantage with everybody else. So, it made it just that much more of a struggle, to try to keep up and not get behind. So, that needs to be addressed, making some of the accommodations more speedy. And that, I think, will also help a lot of students in school as well.

Aran Kundu, a college rehabilitation counselor in the audience, expressed concern about the lack of communication in Washington between the Office of Special Education Programs and the Rehabilitation Services Administration. Although on the same floor, the two departments do not communicate well—children with special needs are growing up to become adults with special needs and are not making the smooth transition from youth services to adult services. NCD members shared their concerns about the transition needs of students identified for special education, which is more of an entitlement system, who then have to move to an adult service system that is not an entitlement system but an eligibility system.

Although colleges and universities receive money from the Federal Government and are covered by Section 504 and the American with Disabilities Act (ADA), they often do not provide adequate support services when students need services for a class or examination. An NCD member noted the responsibility under ADA and 504 for the colleges and universities to provide for students who are not sent by vocational rehabilitation so that any student with a disability has access to needed services, regardless of whether a vocational rehabilitation counselor is involved in that student's education or work rehabilitation plan.

## **JUVENILE JUSTICE SYSTEM**

The Office of Civil Rights in the U.S. Department of Education recently investigated the juvenile justice system in Louisiana and found poor conditions for all youth within those facilities, including a lack of concern about safety and abuse issues. The Office found that special education needs were not being met at all for students with disabilities in the juvenile detention centers. Officials spoke of the opinions of some decision makers in Louisiana regarding these issues. Dr. Dennis reported:

I don't know anything about the safety, but let me speak to education in the state. I tried to pass a bill where we would educate kids that were being housed until they go to trial... and the response from the committee basically was, "We can't educate good kids; why should we educate bad kids?"

Senator Irons added:

Now, the next thing we have to understand, that just like in rural areas throughout this country, prisons are economic engines in small communities. There really is no incentive to educate people or to rehabilitate anybody in prison, because then we will not be able to employ the individuals that live in those rural areas.

### **Mental Health Treatment Needs**

Shannon Robshaw, executive director of the Mental Health Association in Louisiana (MHAL), testified that a Department of Justice report found that Louisiana youth with mental health needs are in danger in the current juvenile justice system. The report found that mental health problems at Swanson and Tallulah secure facilities posed serious risks of harm to the juveniles confined there; that youth with suicidal tendencies and youth engaging in self-mutilation are disciplined with segregated isolation; that juveniles with mental disabilities were inappropriately placed in secure facilities; that youths with extensive psychiatric histories who self-mutilate or threaten suicide are never referred to a psychiatrist; that psychotropic

medications are managed inadequately; and that numerous suicide hazards are found throughout the facilities.

Figures from the state juvenile authorities showed that from 1992 to 1996, the number of youth in Louisiana's Office of Youth Development (OYD) custody and supervision increased from 7,494 to 9,333 (more than 24 percent); that in FY96, OYD spent more than \$70 million to house and rehabilitate juvenile offenders, a 36 percent increase over the FY94 budget; and that OYD increased secure beds by 113 percent from 1994 to 1997.

MHAL has identified juvenile justice as a top advocacy priority for 1998 because youth involvement with juvenile justice is often a result of the failure to provide treatment services to youth with mental health needs. According to the U.S. Department of Justice, approximately 60 percent of the nation's teenagers in juvenile detention have behavioral, mental, or emotional disorders. MHAL has recommended that the state provide more programs aimed at preventing juvenile crime; these programs may not only reduce juvenile crime rates but also the cost of the juvenile justice system. Research has proven that comprehensive, coordinated, community-based mental health services for youth reduce violations of the law; improve how children behave and function emotionally; improve school performance; and reduce the number of costly hospital and out-of-home residential treatment placements.

(**Note:** In March 1997, the Louisiana State Supreme Court heard testimony that a bill passed by the Louisiana legislature in the previous session was unconstitutional. The law allowed juveniles to be transferred from juvenile detention centers to adult facilities upon turning 17 in an effort to relieve overcrowding. The State Supreme Court ruled that the law violated the civil rights of juveniles who had been adjudicated as youth and not tried as adults and that it did not satisfactorily protect these youth from harm. In defense of the bill he authored, Representative Steve Windhorst of Terrytown was quoted in *The Times-Picayune* as saying that, as a prosecuting attorney, he knew the realities of these juveniles and "They're just not lovely children, they really are not.")



Testimony related the difficulties of Verlyn Boyd, the co-director of the Louisiana Federation of Families for Children’s Mental Health, who has been a strong and active advocate for her son since he was diagnosed at the age of seven with onset of childhood schizophrenia. Now 14 and an African-American male who is large for his age, he has enough difficulty processing his environment without processing others’ actions and reactions because of persistent stereotypes and prejudices. Behaviors were expected of him based on his appearance that he was not capable of because of his disability. As a result of impaired judgment related to his disability, he had an incident with the law and is now in the juvenile justice system.

In highlighting the difficulties in obtaining medical treatment and necessary services for mental health issues (covered in depth later in this report), participants pointed out that often families have no other option but to place their children in the juvenile justice system. Parents are instructed that to get help they must declare their youth (some as young as eight years of age) ungovernable and go before a juvenile court judge in the hope of receiving court-mandated treatment. The youth are ordered into the custody of the OYD and placed in juvenile detention centers for treatment and rehabilitation, a very inappropriate placement. Carol Wilson, a parent advocate and state coordinator with Family Voices, expressed her concern about this procedure:

If your child...does not get into the juvenile justice system on their own, they [service providers] tell you that, you can go to court and have your child declared an ungovernable juvenile, and that also is reprehensible to me, because these children are not ungovernable. They have brain disorders, and a brain is a part of the body also. The brain controls what we think and what we feel and how we perceive our world, and it can have a disability. These children, many times, have bizarre behaviors that we’re not comfortable with, and if you are from an ethnic minority population, your problem is compounded because you’re considered, “Oh, all Latinos are hot-blooded,” or “All blacks get into trouble,” or “That’s just that bad kid; that’s the race.”

An audience member identified herself as Brenda Valteau, the president of the Louisiana State Foster Parents Association, and stated that too many young people are going to jail, or are homeless. Her concern was that too many children from ethnic minorities are in the juvenile justice system through lack of appropriate care and treatment.

I visited the Youth Studies Center recently.... It's a center to hold kids until after the court hearing, and out of all the young people I saw there, most of them were males, black males.... Our kids fall behind, because...there's not enough people to help them, assist them, and then they become behavior problems...as a result of not being able to have someone help them to get up to par, academically. So, we're losing a lot of children. Especially...kids in the foster care system.

## **Federal Legislation**

Mental health and child/family advocates brought to the attention of NCD a bill (S. 10) that is being heard in Congress this session. The bill calls for the elimination of most of the funding for preventive and rehabilitative programs for youth. It weakens the language dramatically on the issue of disproportionate representation of minorities in the juvenile justice system. S.10 eliminates the language requiring deinstitutionalization of youth with disabilities and has the potential to perpetuate and worsen the damage done to youth with disabilities in the juvenile justice system.

## **ACCESS TO MEDICAL SERVICES**

All Americans, particularly those with disabilities or chronic illness, need affordable health care that is accessible. People with disabilities face many obstacles in accessing health care, including denial or cancellation of insurance, insufficient benefits, preexisting condition exclusions, and being locked into or out of employment.

### **SSI and Insurance**

The Boykins, a middle-class family from a rural area, quickly depleted their medical insurance after their son was diagnosed with multiple and severe disabilities and was in the hospital for seven months. In the hospital, they were able to access Supplemental Security Income (SSI) for their son, but as soon as they left the hospital, he was removed from SSI. They are in the appeals process while continuing to receive Medicaid, but they have discovered that because of the low reimbursement rates for Medicaid providers, the same doctors who formerly gave first-class care under private health insurance now provide only the bare minimum of medical services.

The family did not have the resources to obtain legal representation and its income was too high to qualify for the pro bono projects or legal assistance. After contacting ACED for assistance with the SSI appeals process, the family received a letter saying that ACED could not help with their son's appeal because it was "not on their priority list." Most issues on the priority list, appear to be concerned with enforcing public compliance with ADA accessibility requirements, and there are a few class action suits for selected concerns. Legal assistance to individuals is virtually nonexistent. If family members are strong advocates, ACED intake workers inform them that because they are knowledgeable and better advocates than many others, they do not need assistance.

## **Children's Special Health Services (CSHS)**

The Boykin family was able to access Children's Special Health Services (CSHS) in Louisiana, where they feel services are a little more personal, but the availability of services is limited in rural areas. A specialist comes to the clinic only once a month, and if the child is sick or cannot make an appointment, the appointment is canceled or rescheduled for another month. There is also no full-time staff at the CSHS clinics. Phyllis Landry, the statewide parent coordinator for CSHS, was present in the audience and explained that doctors are not on contract with CSHS. The doctors receive only \$300 as an honorarium, no matter how many patients they see, and that can range from 1 to 45 per clinic day. The doctors volunteer to work with the approximately 11,000 children with special health needs seen in the nine regional clinics.

## **Tax Equity and Fiscal Responsibility Act (TEFRA)**

The Boykins, like many others, were informed that the only way they could receive SSI was to institutionalize their son because the Medicaid option of the Tax Equity Fiscal Responsibility Act (TEFRA or Katie Beckett waiver) is currently unavailable in Louisiana. This waiver provides a Medicaid card by waiving the income of parents if their child has a disability severe enough to receive treatment in a medical facility but can receive more cost-effective treatment in the home. In 1995, it seemed Louisiana would have a TEFRA program, officials with the Louisiana Department of Health and Hospitals (DHH) and the Louisiana Medicaid office incorrectly insisted to families, agencies, and advocates that TEFRA excludes people with mental disorders. TEFRA was not implemented because of the serious problems uncovered that year in the Medicaid system in Louisiana and the shortfall of funds.

Many people expressed the desire for see the Federal Government to mandate TEFRA in the states as instead of leaving it as a Medicaid option or to separate receiving an SSI cash payment from a disability determination for Medicaid. Under one of these approaches, families

more concerned with the Medicaid card than the SSI cash payment could have equal access to Medicaid. According to Richard Boykin, a parent,

Of course, as you can see, Forrest [his son] meets the disability criteria of SSI, but he does not meet the eligibility of SSI because his eligibility is based on my income. Who is this unfair to? Me? Or is this unfair to Forrest?

## **Medicaid Issues**

Insulin needles at one time were not covered in Louisiana under Medicaid because they were deemed drug paraphernalia. The glucometer to measure the blood sugar of a child with diabetes was not covered at one time either. Karen Divinity, a presenting parent, along with the New Orleans Legal Assistance Corporation, successfully pursued a class action lawsuit to gain coverage of these needed medical supplies.

Karen Higginbotham, a parent, testified that her child was on SSI and also the Louisiana Medicaid Developmental Disability (DD) home-and-community-based services waiver, which provides personal care assistance, respite, home modifications, and other unusual support services. All those on the waiver program expressed their appreciation for the services and support they receive. However, Louisiana has a problem serving those who need such a waiver, as more than 10,000 applicants are on the waiver waiting list. There are presently 200 new slots approved through the last legislative session, bringing the total to 340 of heretofore unfilled slots for the Medicaid waiver. When someone leaves a Medicaid slot, it remains open and unfilled, creating a total of 600 open slots. The Louisiana DHH administration has stated to agencies and families that it doesn't have the manpower to process the applications and fill that many openings.

Youth aged 21 and under on the waiting list who have Medicaid cards can use the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program to access services such as

personal care assistance and respite, but the state Medicaid reimbursement rate for providers of EPSDT services is about half the rate for providers serving those on the waiver. Consequently, providers are refusing to provide the services under EPSDT. Complaints persist that Louisiana Medicaid ignores EPSDT provisions in providing treatment to those with mental health disorders. EPSDT is little understood and mostly believed to be a preventive program. No family training is currently being done in the state regarding advocacy issues for EPSDT and Medicaid services, and people are often not aware of the federal mandates, their protections, or consumer rights and recourse.

### **Rural Access**

In rural areas, access to specialists is limited. Most families travel long distances to metropolitan areas at a great cost in time, stress, and money. According to Ms. Higginbotham,

Opelousas is in St. Landry Parish, one of the largest geographical parishes in Louisiana. Specialized health care and therapy, even support groups for children with disabilities, are quite limited, usually requiring a trip out of town. Many of the pediatric specialists Alison sees or has seen are located either in New Orleans or Baton Rouge. These specialists usually hold clinics in other cities but not in our parish, which can and does present problems with limited or lack of transportation as an issue. A plus is that these specialists, as well as the pediatrician in Opelousas, usually do take Medicaid, which provides her health care.... The faraway hospitalizations require long hours on the road, as well as leaving our other children and incurring meal and lodging expenses. Having to drive out of town for medical appointments can also be time consuming, especially when I worked full time. Out-of-town medical appointments are also hard on Dustin (a sibling), especially since he often has to come along or be left behind with a babysitter.

Because a physical therapist is not on staff in the rural school, children receive those services during school hours at the area cerebral palsy clinic. Although bus transportation is provided to the clinic, some choose to drive their children there to limit the time the children are away from school. Transportation to other appointments continues to be a major difficulty in these areas. Ms. Higginbotham continued:

Although we live in the largest town in St. Landry Parish, there are families only a few miles from us who experience hardship with having limited or no of transportation to and from medical and therapy appointments. Locally, it can be difficult to get physical and occupational therapy. That is because there is no one locally who specializes in pediatric physical therapy and occupational therapy and would feel comfortable with a child with disabilities. It is also a problem because, although some physical and occupational therapists may take Medicaid, they do so on a very, very, very limited basis. Personal care assistants and respite workers are usually unwilling to drive from their base, which is usually in Lafayette, to towns and communities outside of Lafayette. I have gone from agency to agency for personal care assistants and respite services until an agency opened up in my town. This agency has a local pool of workers to draw from.

### **Parental Medical Needs**

Although the child with a disability may qualify for SSI and Medicaid, there typically are no medical services for the parents, who often must leave the full-time work force to care for their child and who often find their health deteriorating in response to the added stress. This is an important issue, especially in low-income, single-parent families where the parent must devote a large portion of time to caring for his or her children, accessing needed services, and advocating for reforms. Ms. Divinity testified:

I don't have a Medicaid card. Ranel has one, but I don't. I have to seek for places to take care of me, because I'm an African-American woman and being subject to the things of age, like diabetes, high blood pressure—all of those things that come along with being impoverished and stressed. And believe me when I tell you, when you have a chronically ill person, whether it is your child, your mother, your brother, your sister, believe me when I tell you there is some stress in that household, and everybody has to live with the stress, so everybody needs care. But there are literally no services available for the parent who chooses to stay home and take care of that child. There is no Medicaid card for me.

### **Mental Health**

Children with mental health disabilities are discriminated against regardless of their race, creed, economic status, or place of residence. Ms. Robshaw of MHAL, which also sponsors the Mental Health Reform Coalition of advocacy organizations working to change the prospects of those with mental health disabilities in Louisiana, spoke on the problems faced in the state:

We know that what works for these children is community-based, comprehensive, wraparound mental health services.... That means working with the schools, foster care, juvenile justice. It's working with the parents and the families; it's providing in-home crisis intervention and in-home support. Family therapy. School-based counseling. All those things—those are the things that we, in fact, know work for children, and have been proven over and over and over again, to improve school performance, to reduce violations of the law, to reduce the number and length of hospital stays. To keep families intact to improve functioning and emotional stability of the child.... The problem is that basically in Louisiana, children are not getting these services.

The driving force behind this lack of community-based mental health services is the federal funding stream. Medicaid requires the state to match federal Medicaid dollars with state dollars for community-based mental health services, but pays 100 percent of the cost of inpatient mental health services for children. This provides a financial incentive to the state to minimize community-based services and maximize hospital services.

According to Louisiana's DHH Office of Mental Health, 86 percent of children with serious emotional disturbances in Louisiana receive no treatment or services. Financial constraints are the primary reason children in Louisiana are not receiving treatment for their mental disorders. Only 6 percent of the DHH public dollars go to the Office of Mental Health to serve both adults and children. The majority of these scarce dollars are being spent in institutions. Louisiana has four times the national average of children's beds in its public mental hospitals.

Only in the arena of mental health disabilities are parents told to give up custody of their children to the state of Louisiana in order to receive medical treatment and services. The children then go into a burgeoning foster care system where many still do not receive services because the services often are not available. Another option is for families to go to court and swear out a complaint that their child is a juvenile in need of care (ungovernable). Judges have the authority to mandate treatment, but when there is no treatment into which to order the youth, the judges, in frustration, order the children into the custody of the OYD and, more recently, into the custody of DHH, which is not a very helpful solution in most cases. The entire process is



light-years behind the rest of the disability community. The trauma experienced by these children and families is unimaginable. The state may save a few dollars, but the cost in human life is tragic.

## **Dual Diagnoses with Mental Health**

When there are dual diagnoses and one diagnosis is a mental health disorder, there is even more cost-shifting between various systems as to who will care for the child. Ms. Wilson testified about the experience of Doug Wilson, her 16-year-old son who has a neurobiological brain disorder and XXY, or Klinefelter Syndrome (a common, though rarely correctly diagnosed, genetic disorder affecting 1 in 600 live male births and causing one or more additional X chromosomes). The difficulty in locating treatment for both his conditions has been compounded because the majority of males with XXY require hormone replacement therapy (HRT) because their bodies do not produce sufficient amounts of testosterone. Males with XXY who are from minorities or who are psychiatrically diagnosed are often denied HRT because of the strong prejudice sometimes found in the deep south that precludes necessary appropriate treatments as well as the lack of awareness of current research on the treatment of XXY. While spending 16 months in the state psychiatric hospital (at the expense of federal disproportionate share hospital funds) because of a lack of community services and comprehensive medical treatment, Doug wrote:

Every day I ask myself, “What’s wrong with me? Why does it have to happen to me?” I never did drugs or alcohol, although I have this disease. Every day it eats away my brain cells. Day by day, I get weaker and dysfunctional. I’m only 15, only I can’t do the things I used to do. I can’t hardly speak any more. Can’t think or do my work in school. I don’t even understand what people are saying when they are talking to me. I used to ace subjects in school, except English. I used to could read and spell. I used to could figure out word problems, puzzles, stuff like that. And I can’t anymore. Deep down inside, it breaks my heart that I can’t do stuff like that anymore. I know from the beginning that you all said you’re trying to understand me better. Well, I’m finally opening up to you. Here’s what you need to do to help me. I need occupational therapy, physical therapy, speech therapy, stuff like that. I think we all should work towards me getting rehabilitated, so I’ll be able to function as I used to. Will you help me, please?

Fortunately, after meeting with several specialists, the family identified a multidisciplinary team willing to work together to meet all the young man's specialized health needs. He is now home and in the community receiving true wraparound services. He was able to receive adequate medical treatment for both his conditions as a result of the assistance and the commitment of national organizations such as Family Voices and Klinefelter Syndrome and Associates to address the needs of families, as well as through extraordinary power advocacy efforts on a national scale. His parents bore the burden of \$300 to \$500 monthly telephone bills for several months in major attempts to locate information, support, and assistance that was limited or unavailable in Louisiana. Few youth in the state are as fortunate.

### **Protection and Advocacy (P&A)**

Questions from NCD on the accessibility of federally funded P&A programs generated the information that attempts to go through ACED have been frustrating largely because family and consumer issues are not high priorities with ACED, the process is too long, and the screening process even to speak with an attorney is often difficult and not consumer friendly. A few years ago, there was a successful ACED class action lawsuit in response to Louisiana's cutting waiver services by 32 percent for respite and personal care assistance and cutting money going into institutional care between 5 percent and 7 percent. Services were restored to those individuals as a result. A class action lawsuit has been filed by ACED on behalf of those on the DD home-and-community-based services waiver waiting list who were not being informed of or receiving EPSDT services through Medicaid if they had a Medicaid card already.

Ms. Shanks of ACED reported that ACED is working to ensure that Medicaid services are provided to all eligible children with disabilities. ACED is involved in representing children with disabilities in the juvenile court system, group homes, and psychiatric treatment facilities. An issue of particular focus and concern for ACED in the past several years involves the discipline of students with disabilities.

For individuals with disabilities, Medicaid or Medicare is usually the only means for health care, durable medical equipment, and assistive technology. A resolution for was presented asking Congress to enact comprehensive health insurance goals. The definition of health care should be expanded from the absence of disease and impairment to include management of a chronic illness or disability. If a funding source for management for chronic illness could be identified that would distribute health care costs equally throughout the population, the Medicaid system would not be overburdened. Unfortunately, Medicaid is associated with being destitute. A concern about how fraud and abuse are hurting those in need of services was voiced, along with a suggestion to continue to implement steps to eliminate fraud and abuse in Medicaid and Medicare.



## **ECONOMIC SELF SUFFICIENCY/INDEPENDENT LIVING**

Parents need economic transition support when their child grows up and moves toward independence. When parents have devoted years to caring for a child with a chronic health condition, they find themselves noncompetitive in the job market. Parents feel strongly that they should be paid to effectively advocate for others and to train others on how to advocate for children with special needs. The emphasis was placed on parents and individuals having become professionals through the school of experience and the need for them to continue doing what they know best while being adequately compensated for it. Working as advocates would also allow parents flexibility in their scheduling needs when caring for their children. Ms. Divinity advocated for such resourceful use of parents:

When you have [an advocacy] position open, call someone like us to do it. And pay us to do it. You know, because we eat the same things you do. We want to drive a car just like you do. We want the same thing—I have to use most of [my daughter's] check to pay for her education. Thank God I have relatives that give me a place to live, and all I have to be responsible for is utility bills. And thank God for those four hours I can work. But I would certainly not mind doing this (advocacy), as opposed to what I'm doing, and letting my talents go to waste.

Because discipline procedures are not consistent and there is a lack of adequately trained teachers and assistants in day care programs and schools for children with mental, emotional, and behavioral concerns, parents are often called from work to take their children home. This causes problems and many people lose their jobs or experience difficulty in locating a job that will allow them flexibility. Several advocates knew of families who were told by employers that the Family and Medical Leave Act was not intended to cover mental health disorders and who were fired rather than being granted medical leave from their jobs to deal with a crisis precipitated by a child's brain disorder. With welfare reform sweeping the country, families are concerned that when they cannot hold jobs or are not afforded the protections of the Family and Medical Leave Act, they will find themselves with no jobs and no assistance. Families would rather work than

be on public assistance, but the way the system is devised leaves many with few options. Myra Edwards, a parent and staff member of Families Helping Families, stated:

There are many parents who are sitting at home, or on jobs, or being called away from their jobs because of their children's behaviors. We need on a national level the support of training and some things that need to go on in school, regardless of what our children's needs are. Regular education, special education, whatever it is. We need to keep our jobs, so we can maintain our family and our homes. A lot of us are single parents. We also need for agencies to fund family-run and parent-run support....

Foster parents of children with special health needs reported that although there are supposed to be programs in place to assist them when they take children with special health needs, the plan often does not translate into reality. These families make a commitment to raising these children in state custody so the children will not have to live in institutions, but the promised support does not come through in time or is insufficient to meet the needs. Foster families face some of the same issues as birth families, and they are told by DHH to depend on social services from the foster care agency to provide for all the children's needs. Yet other child-serving agencies are reluctant to use any of their resources for children in foster care because the assumption is made that the Office of Community Services is providing for these children's needs. There is also a limited amount of funds to serve all children, so there is a shifting of fiscal responsibility between agencies as opposed to collaborative efforts to address all the needs of all children.

Also attested to were the needs of middle-income families who make too much to qualify for public assistance and yet not enough to cover the high costs associated with raising a child with a disability. Families reportedly have lost their life savings, children's college funds, homes, and cars. Families make deep and hard sacrifices to provide for their children and to keep them in the home. Families who pay for insurance that is discriminatory and inadequate or that quickly caps out repeatedly fall through the cracks of the system.

## **Independent Living**

Individuals with disabilities expressed their concerns that to be gainfully employed, some would have to be provided with transportation or assisted with personal grooming. Most affected are those in rural areas where public transportation is limited and there are few providers of personal care services.

Michael Johnson, a student with vision impairment who had worked before becoming disabled, was fortunate to get about \$900 a month in Social Security Disability Income (SSDI), although he mentioned that was only a small part of what he used to make and only a small part of what he could earn when he finished his studies.

I barely get \$900 a month. I was used to living on that almost in two weeks. So that... took a whole change in my life, to take what I'm making in two weeks and try to stretch it for a month. My bills did not change; they only increased. People with disabilities encounter—their cost of living is much higher than people with nondisabilities. First, we have to make arrangements for almost everything that comes—that we have to attend. Just as today, I had to make preparation...to attend this function here today. If I were nondisabled all I would have to do is gas my car up and come down. But it takes more. Those are just small things. With...the subsidies, too, they've got it set up where if I were even to decide to start a savings, if my bank account gets too—too much, they will cut me back. It's almost like they don't want you to advance. That needs to be addressed. Even if I would decide to take a wife. I mean, my check would also be cut as well. They call that an increase of income. I can't figure that one.

All the college students with disabilities who spoke seemed to be under the impression that they would lose their medical benefits if they became gainfully employed at professional levels and lost their SSI or SSDI. They did not seem to have been informed about the protection in the programs that would allow them to keep their medical benefits as long as they needed them. They felt limited in their choices of employment because of their particular disabilities and the limited access to technology, but even more so because of fear of losing medical benefits.

Louisiana has three independent living centers that provide services. One is in New Orleans with a satellite office in Baton Rouge; one is in Lafayette with a satellite office in Lake Charles; and one is in north Louisiana in Shreveport. The total state funding for independent living services is \$190,000, which basically covers running the program. Four core services are provided: advocacy, independent living skills, information and referral, and peer counseling.



## **FAMILY/INDIVIDUAL SUPPORT**

Partners in Policymaking (PIP) is an eight-year-old leadership training program for adults with disabilities and parents of young children with disabilities. It is currently totally funded by the Louisiana State Planning Council on Developmental Disabilities. The program is limited, mainly because of budget cuts, to 25 individuals trained each year. That number has been decreased from the initial 35 persons per year. Agnes Anderson, the director of the program, spoke of a personal commitment to work on budgeting current resources to return to training 35 people in 1998. That would entail many cuts and constraints, but the hope is it will not affect the training of the individuals.

The program is a quality tool provided so people meeting the challenges of disabilities not only can go forth as good personal advocates but also can reach out to other persons in the community and share the information gained from the program. The main focus of PIP is to fully implement person-centered planning for all persons in Louisiana and to empower advocates to be able to speak for what they need, what is best for their household, and what is best for them.

Because of training provided at PIP, families got together in Louisiana in 1989 and ensured the development, passage, and enactment of Act 378, which provided a basis for community and family services and moved away from placement of loved ones in an institution. The Act 378 Task Force, predominantly made up of family members and persons with disabilities, is charged with the oversight of the implementation of the Act's provisions.

### **Family-Centered Approach**

Ms. Haynes, a specialist who works with families of the hearing impaired, spoke of how important it is to always keep the child first and to support families as they support the children. She emphasized the importance of seeing the person first and then the disability. She also

reminded everyone of the need for providers of services to meet families where they are and to respect their cultures and values. Although families and individuals need and want supports, they appreciate it when those supports are no more intrusive than necessary. Ms. Haynes reminded the panels:

When I work with families and parents, it's always the child first and whatever the hearing is, later. But when you talk about the culture, deaf people do have their own language, perhaps their own rules of behavior and traditions, art forms, heroes, and stories. And the community is different. Normally, you would think of a community as a group that are all living together. But because deaf people are in all different areas of Louisiana and all over the country, where do the communities really gather? Lots of times it's in their schools, if there is a large enough group. Where do they meet their role models who are deaf adults? Only one out of ten deaf children have deaf parents. So, lots of times the parents may know no deaf adults.

Respite services are not always provided to many families, and that impedes them in caring for the needs of their children and does not allow them the flexibility to advocate and to locate available resources. Those not on the DD home-and-community-based services waiver experience great difficulty accessing respite. Mr. Boykin, the father of a child with disabilities, mentioned that he had a large family, and so the adult siblings were able to assist and give them for mom and dad a break. This arrangement has both advantages and disadvantages over a stranger providing the service. According to Mr. Boykin,

...the wife and I will cry on each other's shoulders a lot of times. And we turn around and leave, but we feel, like, are they really taking care of him? And of course, they're family members, but are they really doing what they should do? So, can you imagine with a stranger coming in your house, and trying to do something that you're not sure of, is he taking care of him like he should, or, whatever. Family members try the best they can, but they can't do it exactly like we do. And, we've done it so long that it's become second nature to us.

Families of children with special needs are often torn apart because of the high stress levels and lack of emotional assistance provided in coping with the challenges of a child with a chronic health condition, as well as the enormous financial pressures. Lacking healthy coping

mechanisms, husbands and wives can tear at each other and, without emotional assistance and support, may find it difficult to support each other and maintain the marriage or the family unit. Single parents face tremendous challenges because of a lack of support. A child's chronic health condition affects the entire family. The family must be supported to enable it to do what must be done for the child.

### **Case Management**

Although case management services are intended to help address these concerns, in Louisiana, Medicaid limits case management to persons who are already on the DD home-and-community-based services waiver, at-risk infants and toddlers, persons with HIV, at-risk pregnant mothers, and the elderly. People receiving this service are not impressed with its quality, as it requires them to sit at home and wait for one more person to show up. The families' knowledge of resources and their commitment to the well-being of their children is often greater than the providers'. Many times families have done the work while waiting for the case manager to get to them. Some people did report that case managers were helpful in intervening with providers and mediating difficulties. Currently, Medicaid is attempting to limit case management to two providers in each of the nine regions throughout the state to serve all five eligible populations. This reduction will stress an already inadequate system.

### **Self-Advocacy and Support**

Addressing the issue of advocacy and support for students with disabilities, particularly at the high school or collegiate level, Mr. Senigaur focused on the types of available support services beyond a counselor to resolve the questions and concerns that persons with disabilities may have. He proposed the idea of a council in schools where individuals with disabilities could discuss various issues or concerns that they had, share knowledge, and problem solve.

I have found, if you have the support system of peers, you can resolve your problems in an appropriate manner, and it also gives you the confidence that you actually can accomplish and overcome these various barriers.

Foster parents rely on support from other foster parents. Parents rely on the support of other family members. Some people mentioned the nuclear family as the only support they had, and in families with only very young siblings, that is not much adult assistance. Young people depend upon each other for support. All these supports are natural and effective; however, they are limited in scope because of limited funding.

It is essential to the total health of families of children with special health care needs and of individuals with disabilities that all planning be family centered, culturally sensitive, coordinated across all systems of care, and community based. Family and consumer input should be actively sought and respected. Since families practice cost-effectiveness on a daily basis, they often have good insight on how to manage resources wisely. Families and individuals are the largest stakeholders in the process; they have the right to self-determination and the practical need to drive the services that support them.

## COMMUNITY PARTICIPATION

People with disabilities in rural areas face barriers to full community participation because of limited availability of resources and transportation, limited accessibility to some businesses, and limited recreational programs and equipment. They may be restricted in their choices of housing by factors such as transportation, their disability, community prejudice and ignorance, and economic difficulties. Yet, some benefits were given of living in a small town. Ms. Higginbotham testified:

There are positive things that we have encountered in our town, such as living right around the corner from school, and many people knowing one another, which makes us closer knit than those in large cities. Having family nearby, and that some local merchants have helped with some...special needs. Alison is well-known and is greeted by many when we are out in our community. A trip across town can only take a few minutes instead of the long time it can take in a city such as New Orleans.

I cannot end without saying some of the positive things that we have encountered with raising a child with disabilities. Raising a child with disabilities can be challenging; however, it can be rewarding, as it has been for me. Alison is so very special and dear to me, and I cannot imagine life without her. Her spirit and her love have given me strength that I never knew existed within me, and she has taught me to have courage. She has my undying love, and I am proud to be her mother.

Mr. Johnson shared how he has been able to learn braille and cane travel to improve his participation in the community and to foster independence. He has a seeing eye dog he can use in good weather. However, because he was 21 when he lost his sight, the young man found Braille difficult to learn and to use. He does have a talking computer, which is good but has some flaws, just as all technology does. For instance, the scanners are slow, and he requires extra time to do his projects; therefore, he would benefit from being given project assignments early as opposed to being given extensions. There are other problems that also must be considered for the visually impaired to enjoy full community participation, as Mr. Johnson pointed out:

Another major problem we need to think about [with] the technology as far as security reasons...there's no way I can access a bank teller machine without some assistance. They now have a thing that if you use a teller they charge you \$2. So, it's almost like I'm forced, in a way, to pay a fee to use my own bank.

With the implementation of ADA, persons once referred to as “the handicapped” are now referred to as “persons with disabilities.” Changes of attitudes toward individuals with disabilities has contributed to legislative, social, and cultural progress. The Rehabilitation Act, the Fair Housing Act, IDEA, and ADA have promoted more interaction between persons with disabilities with the general public. With increasing public awareness of civil rights laws and available programs for individuals with disabilities, there is greater public acceptance of those with disabilities. However, legislative improvements and the industrialization of society, architectural and attitudinal barriers that are complicated and multifaceted persist. Mr. Senigaur related the following information:

A Lou Harris poll was conducted one and a half years after the passage of ADA and...found that there were a disproportionate amount of negative attitudes toward persons with disabilities. Seventy-four percent felt pity, 47 percent reacted with fear, 16 percent felt anger because people with disabilities inconvenienced them, and 9 percent felt resentment due to...special privileges. However, all individuals polled admired persons with severe disabilities. This general attitude of society raised the question of whether the rehab professionals who were involved with persons with disabilities were also affected by these negative attitudes and biases. And the legislature found out that they were not immune to these negative attitudes, because that's just the normal phenomenon with individuals in society. As far as a resolution to this problem, I would implement classes that would address these issues.

The training of people who work with those with disabilities needs to be examined to promote full community participation. Some people have personal biases for and prejudices against certain disabilities and certain cultures. Providers need to be held accountable for putting forth their best efforts to help all individuals with disabilities because rehabilitation should promote the restoration of a person to his or her fullest potential. If a provider does not have the proper training or education or know the most respectful way to work with people, it will

continue to be difficult for people with disabilities to properly assume their rightful role in society.





## CONCLUSION

The information presented to NCD was candid and thought-provoking. It was evident that the witnesses were courageous, determined, and committed to the cause of improving the lives of persons with disabilities in Louisiana. Even in the face of adversity and multiple barriers, all the families, individuals with disabilities, and advocates were very positive and vested in working with the situations they found themselves in and advocating for the greater good of others. They were self-advocates who had devoted time, money, and energy to learn the rights and responsibilities of persons with disabilities and to share their research with others. The state senator was open to hearing from people with disabilities and their families and to being educated on the issues and the concerns. She gave tips on how to approach her and how to work with the legislature to effect reform. Members of NCD expressed their appreciation to those who testified and the diverse interests that had been well represented.

Mr. Leaf was the last person to testify at the hearing. His testimony was a fitting conclusion to the day:

My message for the Council is just a brief reminder. A reminder that people with disabilities these days have great needs, but they also have great opportunities. As Charles Dickens said, “It was the worst of times; it was the best of times.” We live in an age when the needs of people with disabilities and their expectations have never been so great—probably in part because of the complexity of our society and the difficulty in keeping up with that society—and when government and charitable resources have never been so limited. But we also live in an age of technology—technology that can level the playing field for people with disabilities, enabling them to live full, independent, productive lives, and be an integral part of the communities in which they live. In effect, giving them the capacity to be on an equal, functioning basis with their fellow citizens.



# APPENDICES



## **PARTICIPANT LIST**

Agnes Anderson

Jane Baker, Families Helping Families parent trainer

Richard Boykin, parent

Jerome Brown

Chanise Dennis, graduate student

Rosalynne B. Dennis, Ph.D.

Karen Divinity, parent

Juliette Haynes, Parent/Pupil Program, Louisiana School for the Deaf

Karen Higginbotham, parent

The Honorable Senator Paulette Irons, Louisiana Senate

Michael Johnson, student

Shannon Robshaw, Mental Health Association in Louisiana

Debra Scott

Rodney Senigaur, college student

Mary Shanks, Advocacy Center for the Elderly and Disabled

Karen Trudeau

Carol Wilson, Family Voices



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