



facing families. The delegates stressed that job stability and good housing are critical components of health. Parents need family sick leave policies and release time to obtain the services they need. Housing ordinances need to be enforced. Also needed are better daycare services and respite care services for overburdened parents.

Several regions considered some untraditional ways to improve communications to facilitate transitions. Region 4 delegates made a unique recommendation: Involve parents in peer group visitation programs. One mother told how her community solicits experienced parents to visit the homes of new parents and offer friendly, nonthreatening advice about programs, services, support groups, and organizations that are available to them. These visits, she added, are made to all new parents, not just parents of children with special health, education, or financial needs. The parents from the southeastern States also pointed out the importance of families' making time for children between transitions; everyone needs a break, they said, especially when a transition involves a change in marital status, living arrangements, or health care.

Some model programs cited by the Region 4 delegates include Kentucky's Family Resource and Youth Service Centers, created as part of the Kentucky Education Reform Act and operated through the schools to benefit children and families at risk; the Eastern Kentucky Child Care Coalition, a private resource development agency that offers training and assistance to childcare providers and families; and Mississippi's Families as Allies, a network of families with special needs children. The Florida delegation shared materials on several public and private programs from their State: Infants & Toddlers; Florida's Interagency Program for Children and Their Families, which has established the Directory of Early Childhood Services, accessible through an 800 telephone number; Collaborative Adolescent Parenting Program (CAPP), an intergovernmental, interagency, community-based effort to support teenage parents; Family Connections, which provides services to low-income teenage parents, and Family Interaction Now (FIN), a family support program for recovering pregnant and postpartum addicts, both sponsored by the Child Care Connection of Broward County, Inc., a private, nonprofit organization that supplies Title XX childcare; Casa Madonna, an aftercare program for Hispanic substance-abusing mothers, which is sponsored by the Miami Mental Health Center, Inc.; The Bridge, sponsored by Family Health Services, Inc., which provides a mix of services to young mothers and their children; and Project MITCH (Model of Interdisciplinary Training for Children with Handicaps), which provides training to parents and other care givers, through funding from the Florida Department of Education to the Florida Diagnostic and Learning Resources System/South. In addition, the Department of Health and Rehabilitative Services sponsors First Steps and the Community Resource Mother or Father Program.

## REGION 5

ILLINOIS


INDIANA

MICHIGAN

MINNESOTA

OHIO

WISCONSIN



Delegates from Region 5 agreed that parenting skills should be part of every child's schooling and that resources should be available for the continuing education of parents in these skills. Better parents will become a stronger and more effective presence in their communities. They will assume greater responsibilities in their local school systems, both in policymaking and in day-to-day participation, to help counter the chaotic forces that act on children as they enter adolescence. The Region 5 delegates complained that the middle class is excluded from services. They stressed that everyone needs access to adequate health care and that our Nation should provide "equal education for all." They pointed out that the goals of the Surgeon General's initiative should go beyond the year 2000. Other barriers to entry into the systems that

they cited are long waiting lists for services and inflexibility of the systems. They recommended a one-stop-shopping approach to services with providers who are informed about available resources. They suggested producing a guidebook of services and including a directory of local services in every community's telephone directory.

As families participate in programs, the delegates asserted, education should accompany the services rendered. They complained that the programs are not family centered, and that parents who act assertively to have their needs met are isolated. The social

### Region 5

## Recommendations at a Glance

### Awareness and Entry

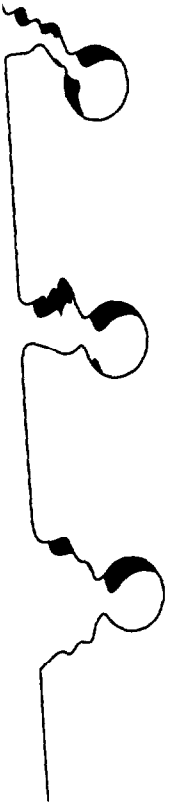
- ★ Provide training in parenting skills for all children
- ★ Don't exclude the middle class from services
- ★ Continue the Healthy Children Ready to Learn Initiative beyond the year 2000
- ★ Implement one-stop shopping
- ★ Produce a guidebook of services and include a directory of local services in community telephone directories

### Participation

- ★ Accompany services with education
- ★ Provide mechanisms for parents to get answers for questions or to voice complaints
- ★ Allow greater parent involvement in policy decisions
- ★ Forge stronger links among schools, social service systems, and local business
- ★ Prioritize needs before spending funds and make programs accountable for how funds are spent
- ★ Provide for unbiased evaluation of programs
- ★ Address the causes of families' problems and provide healing, not "band-aid fixes"

### Transitions

- ★ Teach basic life skills, beginning at an early age, to prepare children to parent the next generation
- ★ Support parent networks and outreach programs
- ★ Appoint Dr. Novello as the Administration's advocate for families



## HEALTHY CHILDREN Ready to Learn



service system was criticized for having no built-in mechanism by which parents can get answers to their many questions and a sympathetic ear for their complaints. The systems are generally perceived as bureaucratic, rigid, and insensitive. Parents need to play a greater role in policy decisions and act as advisors to programs. For instance, many of the delegates felt that parents should work with their schools to explore the possibility of dress codes and establish other policies. When this group discussed the parental role of being an advocate, they commented that parents need to take this responsibility to the fullest. They must be involved in the school or program, know everyone from school board members to administrators to teachers, and become a presence in their child's education. Schools, in turn, need to forge stronger links with the social service systems and local businesses. Another important issue to the Region 5 delegates was that needs must be prioritized before money is spent, that programs must be accountable for how the money is spent, and that programs should be evaluated by unbiased parties. The delegates expressed that programs must address the underlying causes of problems families face and that services should provide healing as families participate, not give them just a "band-aid fix."

The Midwestern delegates repeatedly said that parents need to begin at childhood to prepare their children for the ultimate transition from child to parent. They advocated reaching out to children to show them how to be parents and to explain the responsibilities that go along with the role. They recommended that schools teach basic life skills, beginning at an early age, so that children will be prepared to parent the next generation.

These parents also stressed that communication among parents and between parents and programs is key to successful transitions. They stated that strategies to improve communication should include outreach programs to draw new families and to truly affect the community. Region 5 delegates looked to the Surgeon General to be more than a partner with them in making healthy children ready to learn. They agreed that she must be the administration's advocate for families. She must be among the ranks of people who hold health, education, and social service systems accountable for ensuring that children and parents can make transitions between programs smoothly.

Model programs cited by the Region 5 delegates include the Illinois Governor's Education Initiative, which involves parents in school policy decisions. Under this program, 35 communities discussed the reallocation of funds to allow State agencies to coordinate their efforts and develop stronger ties with the school system. Another Illinois program, Families With A Future, funds prenatal care, home visits, a children's clinic, nursing care, and certified advisers who coach mothers as they enter the social service system; volunteers provide transportation. In Minnesota, the Leave No Child Behind program funds learning readiness. Other programs in Minnesota include Challenge 2000, Parent Involvement, and Learning Readiness. The Ohio delegates cited Family and Children First, and Indiana parents praised the Indiana University Medical Center's James Whitcomb Riley Children's Hospital as a model for caring for sick children and supporting the families during times of crisis. Michigan programs include the Latino Outreach Program in Detroit and Project Uptown.

## REGION 6

ARKANSAS

LOUISIANA

NEW MEXICO

OKLAHOMA

TEXAS



Region 6 delegates asserted that families should be a nationwide priority. They also strongly advocated regulation of the insurance industry. Insurers can raise rates, deny coverage, and cancel policies arbitrarily, with the result that families either cannot afford health care or have to enter the social service system and sometimes give up jobs and income to meet rigid eligibility criteria. The delegates also pointed to low levels of private participation in health care services, saying that if providers were reimbursed at competitive rates, the services would improve across the board. The providers need to be better informed about available services and ready to pass that information on to families. A resource directory and a toll-free information hotline in each State were strongly recommended.

In addition, health care providers should be coached and sensitized by parents who are participating in and have experience with the systems. At present, families are not perceived as partners with providers and do not feel respected. The delegates warned that parents with regional accents have to be careful that they are not perceived as less intelligent merely because their pronunciation is different or their speech patterns are slower. The point of contact for services (both for parents entering the systems and those already participating) should be an individual who is

### Region 6

## Recommendations at a Glance

### Awareness and Entry

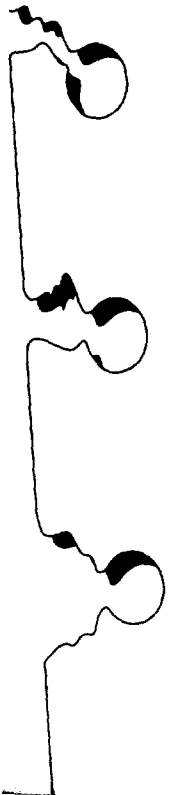
- ★ Regulate the insurance industry to prevent arbitrary cancellation of health insurance policies
- ★ Encourage private participation in health care services by reimbursing providers at competitive rates
- ★ Provide better informed service providers
- ★ Develop a resource directory and establish a toll-free hotline

### Participation

- ★ Recruit parents to coach health care providers in sensitivity
- ★ Provide individuals who are representative of the community to be the point of contact for services and evaluation of programs
- ★ Orient services around family needs by locating facilities together in convenient locations
- ★ Allow parents more creative input and policy input and the opportunity to evaluate programs

### Transitions

- ★ Maintain effective communication between parents and caregivers, particularly for foster parents
- ★ Provide mainstreaming for children with special needs in all communities
- ★ Form partnerships among agencies that provide health and medical care to better serve families





representative of the local community. Services are not oriented around family needs; families have to travel long distances to appointments because of the limited number of providers in these States, and then they are forced to wait and waste time. Services should be located as near families' homes as possible. Why not set up on-site facilities so that parents can attend to other important family business, such as doing laundry? The delegates insisted that parents need more creative and policy input into the systems and should be given the opportunity to submit evaluations of providers.

There was national consensus that successful transitions begin at home, but Region 6 delegates States added the advice that some situations demand special efforts. They commented that foster parents must be careful to validate their children's feelings at all times. Foster children have an extraordinary need to develop their self-esteem. Without this esteem, the parents said, children will not get the maximum benefit from transitions. Communications with children and caregivers has to be two-way. While it is imperative that parents be vocal advocates for their families and recognize their power as parents, these delegates agreed, it is also

critical that they listen to the children and the professionals taking care of them. Parents in Region 6 also pointed out that mainstreaming is not available in all communities, but it is a universal right of children to be allowed to mainstream. Parents, they said, need to demand this right for their families. The Region 6 delegates stressed that access issues must be addressed and that agreements are needed among agencies to form health and medical partnerships to better serve our Nation's families.

The Children's Hospital in Arkansas, which already has a hotline, was cited as a model program. Other Arkansas programs include Arkansas Better Chance, Child Find, Children's Medical Services, and Focus in Blytheville. Adult Learning Center in Shreveport, Louisiana, combines infant care, literacy training, and a welfare office. Dallas, Texas, has a quality infant care program for teenage mothers and helps them with the transition to Head Start. Another Texas program cited was the Childcare Management System in El Paso. Oklahoma programs include the Institute for Child Advocacy, Sooner Start, and Oasis.

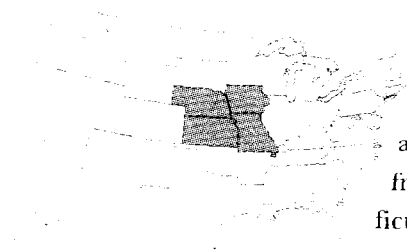
## REGION 7

IOWA

KANSAS

MISSOURI

NEBRASKA



Long distances to health care centers are a problem in this part of the Midwest, and the quality of services is uneven in urban and rural areas. The lack of coordination among services forces parents to make frequent visits, compounding their difficulties. Eligibility requirements are inconsistent from State to State, and parents who relocate in new communities have to repeat the lengthy application process. Because information on services is lacking, in Missouri, some neighbors go door to door with flyers and other information.

As families participate in programs, the Region 7 delegates recommended that parents seek an ally who can be relied upon to supply accurate information. In turn, parents should share their knowledge of the programs with others. Parents also have a responsibility to establish a positive interaction with the caseworker to give feedback

on the services received. In developing these relationships, however, they warned that parents must keep their first priority and maintain a balance between participation in program activities and family life. They feared that parents might fall into the trap of trying to do everything and warned that providers should not overwhelm parents with too much information and too many activities at the same time. Parent involvement in program planning would help prevent these problems, they said, and parents also should help set goals for the programs.

### Region 7

## Recommendations at a Glance

#### Awareness and Entry

- ★ Reduce distances that families must travel for services
- ★ Improve consistency of services from urban to rural areas
- ★ Improve coordination of services
- ★ Make eligibility requirements consistent from State to State

#### Participation

- ★ Promote parent support groups
- ★ Don't overwhelm parents with too many activities
- ★ Involve parents in program planning
- ★ Provide more year-round programs
- ★ Provide full-day Head Start or locate Head Start together with Title XX or other childcare programs
- ★ Provide childcare for special needs children

#### Transitions

- ★ Seek information from parents about children's specific needs
- ★ Provide honest answers to parents' questions rather than "beating around the bush"
- ★ Develop a national policy modeled after the Nebraska Family Policy Act
- ★ Promote partnerships, including parent-to-professional groups, professional-to-professional groups, agency-to-agency collaborations, community-to-community partnerships, and State-to-State partnerships

The Region 7 delegates expressed a need for more year-round programs for their children. They also suggested full-day Head Start programs or collocating Head Start with providers of Title XX or other childcare programs. They would like to have childcare available for their special needs children so that they can attend activities in which their "normal" children are involved. They described how special needs children are often denied activities simply because they are labeled as disabled, even though the parents think they are capable of participating. For example, one mother shared that her child was not allowed to ride a horse even though her husband was planning to ride with the child and take full responsibility for the child's safety. They urged that we "put labels on cans, not on children."

Like delegates from other regions, these parents said that, to ensure smooth transitions, they must be good recordkeepers and make sure their children's needs are communicated when records are transferred. Because those needs are not always part of an official record, parents must alert professionals to them. For example, health care professionals may be proficient at doing G-tube feedings, but a parent may be the only one to know that his or her child needs to be fed for 10 minutes, then rested for 10 minutes, before finishing the feeding. Caregivers might know how to get a child ready for bed, but parents know which children won't go to sleep without their teddy bears in hand. At the same time, caregivers need to communicate fully with parents. These parents prefer honest answers to their questions. They insisted that caregivers should "tell it like it is" and not "beat around the bush," particularly when the information concerns their children.

The delegates agreed that a model program would have a single point of entry even though a family might need a dozen or more services. The model program would cover all needs and disabilities and be based on the philosophy that the systems should adjust to the needs of the family. There would be a single set of paperwork for all services and a resource coordinator assigned to each family to help the parents through the bureaucratic maze. Prescreening of infants and Child Find services should be made available to all parents.



They cited the Nebraska Family Policy Act, which coordinates all services to needy families, and recommended that a national policy modeled after this act be developed. These delegates also expanded the idea of parent support groups and partnerships to include parent-to-professional groups, professional-to-professional groups, agency-to-agency partnerships, community-to-community partnerships, and State-to-State partnerships.

Kansas' model programs include Parents as Teachers, Healthy Start, the Parent Training and Information Center, and Keys for Networking, all in Topeka. In Omaha, Nebraska, the First Step Infant Health Care Project has prenatal programs and integrated services for low-income mothers living in public housing. Under Missouri's First Steps program, resource coordinators come to the home and explain available services to parents. In St. Louis, Missouri, the Human Development Corporation, Parents as First Teachers, and the Parent/Child Center were recommended. Missouri and Nebraska each have information hotlines: In Missouri the hotline is called Parent/Link. Kansas also has a Resource and Referral System hotline. The Nebraska Family Support Network was cited as a model support program. Missouri's Parkway Early Childhood Programs and Early Childhood Organization (ECHO) are successful model programs. Iowa has the Early Childhood Special Education program, the Parent Infant Nurturing Center, the ARP Respite Care Training Project, and Up With Families.

## REGION 8

COLORADO

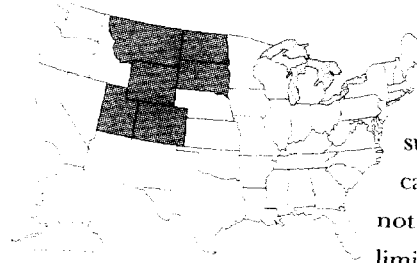
MONTANA

NORTH DAKOTA

SOUTH DAKOTA

UTAH

WYOMING



Delegates from these western States were concerned about the availability, quality, and cost of health care in America. They pointed out that getting families covered with health insurance is a need and a solution. They cautioned that health insurance should not be confused with Medicaid, which is a limited resource. In comparing Medicaid with health insurance, they pointed out that health insurance allows access to health care; Medicaid does not guarantee that access. Health insurance covers preventive care; Medicaid does not. Going hand in hand with the problem of health care costs is the concern that liability has become a real problem in the United States. The doctor's fear of being sued for damages is increasing costs for parents and communities.

These more sparsely populated States have several problems in making families aware of services and

enlisting their participation. Families living in rural areas often have to rely on word-of-mouth for information on available services: A toll-free hotline would be a useful solution. Each State should have a free clinic system with an interagency coordinator to provide parents with information and help line up State services.

Region 8 delegates also urged greater involvement at the community and local level, not only for individuals but also for local businesses. They recommended that local business leaders

### Region 8

## Recommendations at a Glance

#### Awareness and Entry

- ★ Provide affordable health care for all families
- ★ Establish a toll-free hotline
- ★ Establish a free clinic system with an interagency coordinator

#### Participation

- ★ Encourage support from local businesses for programs such as childcare
- ★ Extend programs such as Girl Scouts and 4-H Clubs to all communities and provide funds for families who can't afford to participate
- ★ Involve parents in program design and planning
- ★ Involve parents in programs to visit new mothers and serve as their mentors
- ★ Expand hospital funding to provide followup care

#### Transitions

- ★ Seek information from parents about mechanisms that trigger certain behaviors in children
- ★ Provide training in parenting skills and nutrition as part of the basic school curriculum
- ★ Encourage religious bodies to conduct parenting training and help parents build a positive parenting vision
- ★ Encourage Americans to become a nation of learners
- ★ Mingle Federal, State, and local funds to support programs
- ★ Run programs as businesses are run, with measures to ensure that their objectives are being carried out





support childcare centers, for instance. They suggested that community programs such as the Young Men's Christian Association (YMCA), the Girl Scouts, and 4-H Clubs be extended to all communities and that funds be provided to families who cannot afford these programs. They recommended that parents lobby within their communities to sensitize leaders to the importance of the family as the basic building block of the community. They stressed that parents should be involved in program design and planning. An example of veteran parent involvement would be to visit new mothers in the hospital and serve as mentors. They also stated that hospitals need to allocate funds for followup care.

Like the parents from Region 7, the Region 8 parents said that it is their role to inform programs about their children's particular behaviors and needs that might not be part of an official record. These delegates talked about the importance of informing new service and care providers, before the transition takes place, about trigger mechanisms that evoke certain behaviors and ways the parent has found to control behavioral problems. Transitions can be difficult and become a monumental hurdle to a family's development. When a transition is made, these delegates said, families need to celebrate their mutual or individual achievement.

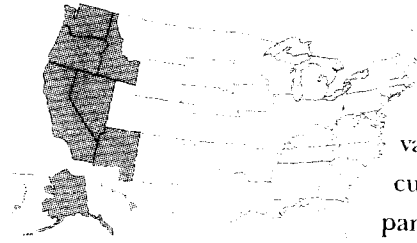
The Region 8 delegates advocated that training in parenting skills and proper nutrition should be part of

the basic school curriculum. Furthermore, they maintained that parental education is a role that religious bodies should assume. Part of that education, regardless of its source, should be to help parents develop a positive parenting vision. It would be wise for educators to remember that not every parent's childhood lends itself to such positive experiences and that not everyone has an instinctive vision about parenting. This group looked at education in America and declared that we must become a nation of learners. Parents need to redevelop their own enthusiasm for learning if they are going to create such an enthusiasm in their children. The Region 8 delegates cited a need for more mingling of Federal, State, and local funds to support programs. They also added that programs should be run in a manner similar to businesses, with measures to ensure that those who use the programs are receiving the value that they are intended to provide.

Existing model programs they cited were Partners in Leadership, Family Resource Centers, Effective Parents Project, Parent Education and Assistance for Kids (PEAK) Parent Center, the Disability Information and Referral Service (DIRS) Hotline, Connect, and El Groupa Vida in Colorado; Ask A Nurse and First Steps in Montana; Tracking in North Dakota; and Baby Your Baby in Utah.

## REGIONS 9 AND 10

ALASKA  
AMERICAN SAMOA  
ARIZONA  
CALIFORNIA  
GUAM  
HAWAII  
IDAHO  
MARIANA ISLANDS  
NEVADA  
OREGON  
WASHINGTON



Region 9 and 10 delegates argued forcefully that health care and social service systems should recognize and value native language differences, local customs, and family values. Most systems show a marked cultural insensitivity and fail to involve parents in decisions that affect their children. Social service workers need to be more compassionate, and they need to encourage the growth of community-based programs. Eligibility criteria need major overhauling. The criteria are based on artificial standards (income levels versus need) and lead to unfair labeling and inequities in services. Regional cost of living differences are not taken into account. They maintained that families who need the services most often cannot participate.

Like parents in other regions, these delegates complained about the lack of coordination of services; duplication of some services confuses recipients and forces providers to compete for funding while gaps exist in the provision of other services. Furthermore, they maintained that the distribution

of services around the country is uneven. They also voiced a desire to participate in the design and planning for programs, including involvement in curriculum development, hiring, and budget decisions. At the same time, parents must ensure that service providers have a full understanding of their children's needs. They also maintained that the parents have a responsibility to be advocates, not only for their children but also for the programs in which they participate, and to lobby for these programs.

The delegates from the Far West and

### Regions 9 and 10

## Recommendations at a Glance

#### Awareness and Entry

- ★ Recognize and value cultural differences
- ★ Involve parents in decisions that affect their children
- ★ Overhaul eligibility criteria, basing eligibility on need rather than income and considering regional cost-of-living differences

#### Participation

- ★ Improve coordination among programs
- ★ Distribute services more evenly throughout the country
- ★ Involve parents in program design and planning
- ★ Encourage parent advocacy

#### Transitions

- ★ Help fulfill basic needs such as housing and health care
- ★ Improve collaboration among agencies and consistency across agencies
- ★ Provide referral persons within agencies to help families deal with transitions
- ★ Increase public sensitivity to family problems such as divorce, substance abuse, unemployment, or incarceration of a parent

Pacific protectorates shared their concerns about the overwhelming responsibilities of being parents. They said that parents need hope to get them through daily living and especially in situations when transitions are involved. To give families hope, Government agencies and other service providers need to help them fulfill basic needs, including those for housing, health care, and nutrition. These parents also noted the lack of collaboration among agencies and the lack of consistency across agencies, both of which make transitions more difficult. They cited a need for referral persons within agencies to help families deal with transition issues. The Nation as a whole (especially all people caring for its children) needs to comprehend the effects of such family problems as broken homes and substance abuse; special concerns of parents who are incarcerated or unemployed need to be understood and taken into consideration when transitions are necessary. Parents have a responsibility to network and to be team players in helping to provide services, particularly during times of transition. Like the delegates

from other regions, this group maintained that parents must maintain information about their children, and they must prepare their children for transitions.

A model program would allocate funds for parent networks, especially among minority groups; involve local media, churches, and other community organizations, including police, to disseminate information; involve greater parent participation; reduce paperwork for applicants; ensure that programs and services are better coordinated; and respond to information requests in a timely manner. Examples of model programs cited by these delegates include the Murphy School District in Phoenix, Arizona; California's Healthy Start Support Services for Children; Even Start in Blackfoot, Idaho; the Maternal and Child Health Program, Handicapped Children's Resource Center, and Referral for Services in the Mariana Islands; and the Washoe Pregnancy Center in Reno, Nevada.

## HEALTHY CHILDREN - Ready to Learn



## NATIVE AMERICAN FAMILIES

*The highlighted States or areas within States are those that contain reservations or a large population of Native Americans. More than 60 percent of Native Americans live off the reservation in both urban and rural areas.*



Native American delegates identified the search for information as their overriding issue. Parents with special needs children feel particularly at a loss, and there are too few programs for newborns. Social service systems in Oklahoma and Montana fail to provide Native American parents with comprehensive information on available services, and transportation to health care centers is a serious problem in isolated areas. Supplemental foods are also hard to obtain in these areas. Non-Native American doctors and dentists often refuse to provide services to Native Americans and those who do serve Native Americans are concerned primarily with paying off scholarships and show little compassion toward or understanding of their patients. Housing, especially housing provided by the Department of Housing and Urban Development, is often inferior.

These problems result in and are compounded by problems such as a high rate of substance abuse among mothers, including paint and glue sniffing, which often is undiagnosed. Teenage pregnancy rates are also high, and Indian parents seem to have difficulty communicating about sex with their youngsters. The community's lack of compassion for these young mothers lowers their self-esteem. Furthermore, they often don't realize the need for prenatal care and don't know how to adequately care for their babies.

### **Native American Families**

## **Recommendations at a Glance**

### **Awareness and Entry**

- ★ Provide comprehensive information on available services
- ★ Address transportation problems
- ★ Make obtaining supplemental foods easier in isolated areas
- ★ Increase the number of doctors and dentists who serve Native Americans
- ★ Improve housing provided by the Department of Housing and Urban Development
- ★ Improve the detection of substance abuse among mothers
- ★ Provide sex education for teenagers and increase the number of mothers receiving prenatal care

### **Participation**

- ★ Increase funding for programs
- ★ Target funds for programs specifically for Native American children
- ★ Improve cultural sensitivity
- ★ Address communication problems

### **Transitions**

- ★ Protect confidentiality while instituting a national database for social services
- ★ Recognize the status of tribes as separate nations
- ★ View parents as educators of cultural heritage

As a result, many Indians begin life at risk and remain so all their lives.

Native Americans feel that funds to combat these problems are allocated on the basis of head counts alone and that services are uneven and often discriminating. More funding was a universal recommendation. The Native American delegates added that some funds need to be clearly targeted for Indian children so that all their children's needs can be met, regardless of family income or tribal programs. As the 1990 census indicates, more than 60 percent of Indians live off the reservations in both urban and rural areas. In urban areas, the Indian community is culturally diverse, sometimes representing several tribes and languages. Providers need to be aware of this cultural diversity, and services should be provided in these urban areas. One delegate told about being denied special health services because a provider insisted that she use the reservation hospital, which did not offer everything her condition required. Another delegate told of a person who had facial characteristics of an Indian but did not have a tribal heritage; nevertheless, he was sent to the reservation for services.

Indian delegates reminded their white and African-American colleagues that, as Native American parents participate in programs, acting assertively to confront the system and demand that it become responsive defies tribal heritage and culture. Native American parents will not be assertive merely because someone tells them that they must. However, this problem can be resolved if Native American parents accept the role of teachers for practitioners who don't understand tribal customs and history. It is imperative that service providers be taught that it is contrary to tribal culture for a person to look directly into another's eyes when he or she speaks because social service providers have been known to doubt a person's honesty because he or she did not maintain eye contact with the practitioner and deny benefits. Other unique communication barriers include the loss of information or misunderstanding during translation, especially when all words in tribal languages do not have an English equivalent, or vice versa. Programs and the materials they use need

to be tied to cultural relevancy both for children and parents.

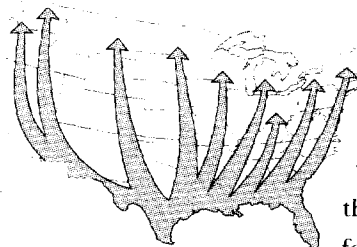
Although confidentiality in health and social service programs is a concern for all parents, it is particularly important for Native Americans. Confidentiality is sometimes threatened when the programs are administered by the tribe because the providers and recipients of services are often acquainted or even related. Holding tribal staff accountable is very difficult. Nevertheless, these delegates, like their colleagues in all the other regions, said a national database network for social services is needed; however, they advised that regulations ensure confidentiality among all services and programs.

In another area, services and programs must recognize the distinct status of tribes as separate nations. The delegates said that professionals need to be aware of and address issues of racism, and the system needs to begin to see Indian parents as prime educators, especially educators of cultural heritage. Practitioners and professionals tend to show little respect for the use of elders for teaching tribal nations, they added.

Head Start and WIC are considered model Federal programs. Newer programs that seem to be working well include Wisconsin Indian Network Genetic Services (WINGS) (in Wisconsin and Oklahoma), which identifies special needs children and helps coordinate services for them; the Trails program, an Outward Bound program; National Indian Youth Leadership, a New Mexico model for youth leadership and mentoring; and Indian Child Welfare programs, aimed at keeping Indian foster care and adopted children in Indian families. The HomeBound and Babies Having Babies programs in Oneida, Wisconsin, both serve teenage mothers. Oklahoma has excellent referral centers in the Tulsa Indian Health Care Resource Center and the Oklahoma City Indian Health Clinic. The Pawnee Benefits Program issues benefit cards that can be used for care by a private physician.

## MIGRANT FAMILIES

The arrows on the map indicate the general routes followed by Migrant families as they travel to work during the growing season and harvest of America's crops.



Migrant families also have their own special set of issues of concern, with housing, salaries, health insurance, and injured workers benefits taking the lead. Migrants often must rely on crew leaders who recruit teams of workers and then may exploit them, denying them basic rights (such as forcing them to work on Sunday when they want to attend church) and charging them for free services (such as housing provided by the farm owners). Migrants were largely overlooked in the 1990 census, and the low level of available health care and social services reflects this deficit. The lack of coordination between programs from State to State affects Migrants particularly: They cannot qualify for WIC, Food Stamps, or Medicaid benefits in one State without canceling their benefits in another. If they return to a State, they have to reapply. Migrant parents need some kind of

resource material, available before they move, that would provide them with a State's regulations and policies. Federal programs also should be coordinated with the needs of Migrants in mind. For example, the U.S. Departments of Health and Human Services, Agriculture, and Education each define a "migrant" differently, which leads to confusion and causes denial of benefits. Support groups for Migrant families sorely need funding.

Migrant workers who do participate in programs find that they often must travel long distances to obtain services and miss

### **Migrant Families**

## **Recommendations at a Glance**

### **Awareness and Entry**

- ★ Improve housing conditions, salaries, access to health insurance, and injured workers benefits
- ★ Provide controls over mistreatment by crew leaders
- ★ Increase available health care and social services
- ★ Increase coordination of services among State and Federal agencies
- ★ Provide resource materials on each State's programs
- ★ Provide funding for support groups

### **Participation**

- ★ Provide conveniently located facilities
- ★ Address transportation problems
- ★ Examine policies and implementation of food stamp allocation
- ★ Make Food Stamps available for distribution through the post office
- ★ Address communication problems by providing more bilingual staff
- ★ Enforce child labor laws and keep children in school
- ★ Provide daycare services

### **Transitions**

- ★ Provide improved access to programs and other mechanisms to help migrant families prepare for transition
- ★ Make transfer of school credits uniform among States
- ★ Improve sensitivity to migrant families' problems and show respect
- ★ Hold a followup conference

whole days of work. Transportation is often hard to obtain. Crew leaders often do not allow parents time off to attend meetings. Migrants are often subjected to illegal treatment regarding Food Stamps allocation. One delegate recommended that Food Stamp distribution be alphabetized for pickup at post offices, so that recipients do not have to spend hours waiting in line. Communication is often a problem for Migrants because service providers lack enough bilingual staff or have no one who can speak the client's language.

Keeping Migrant children in school is a pressing issue. Child labor laws are not enforced; children as young as 10 or 11 years are hired to work in the fields. Parents often have no recourse but to have their children work; their family's livelihood depends on their harvesting as much as possible, and each pair of hands adds to their production. This problem is compounded by the lack of daycare for Migrant families. The result is that small children are brought to the fields along side working mothers, or they are left in the care of children who are too young to work, and who are not much older than their charges.

Migrant families, their conference representatives pointed out, face transitions that are almost always double-edged; they are geographic as well as developmental. Migrant families are constantly making transitions and that means new rules and new environments for their children without any mechanisms to prepare for the adjustment. This continuous movement means continually losing friends and family support.

This delegation commented that it is particularly important for their parents to be guardians of children's records. It is common for Migrant families to complete and file all the paperwork necessary to receive public assistance, only to have the growing season change and force a move to another State before the assistance starts. When they get to the new State, they added, the paperwork has to be redone. But guarding the records does not always guarantee that they will be transferred easily or correctly. These delegates said school credits do not transfer from State to State very easily or uniformly, especially when students enroll in a new school in the middle of a term. Migrant parents recommended

that the U.S. Department of Education devise a system that allows classes and credits to transfer from other States. These delegates also called for improved access to routine programs as a way to make transitions smooth. They said that bad health conditions and no daycare, after-school care, or social services are the norm for communities where Migrant workers live. They urged that employers of Migrant workers be closely monitored regarding their employment practices, facilities, and use of pesticides.

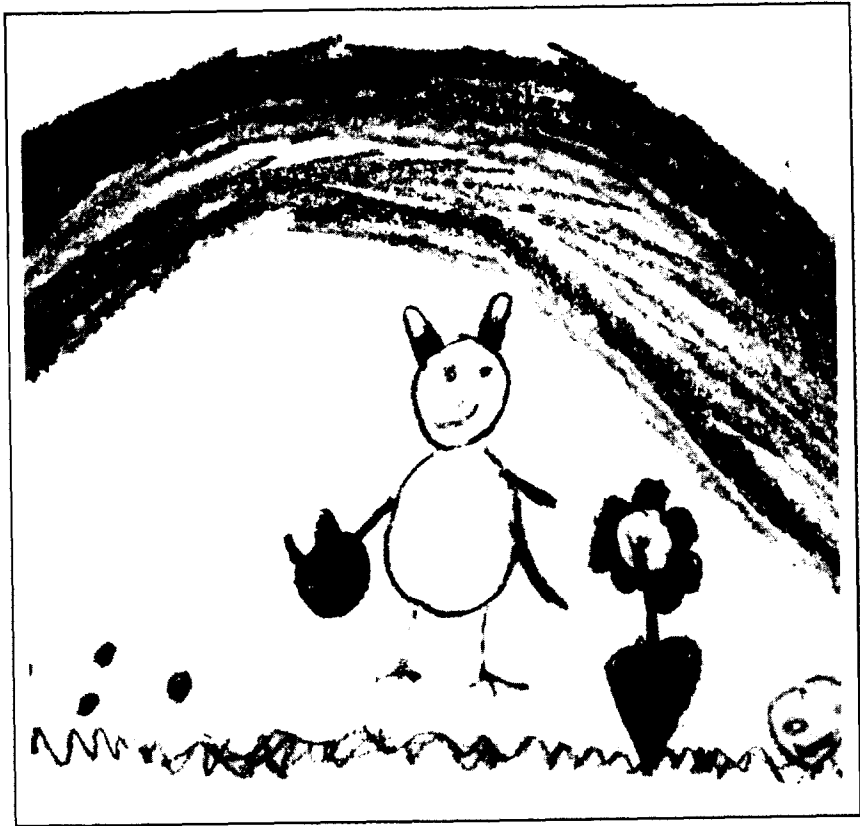
For Migrant parents, developing children's self-esteem often entails demanding respect for Migrant families in general from teachers and other caregivers or service providers. They complimented the conference cosponsors for including Migrant issues on the agenda, saying that more of these opportunities are needed. They urged the continued participation of Migrant families so that they can be partners in raising healthy children ready to learn.

The families agreed that a model program should include classes in prenatal care, dental care, and English as a second language; make Head Start available for all Migrant children; involve parents in policy decisions; bring mobile health clinics to rural areas; fund senior centers for care for the elderly; and sensitize social service staffers to the special needs and cultural differences of Migrant workers. Migrant families are subjected to exceptional stresses and strains, and model programs should take care to address the needs of the family as a whole, to help maintain family integrity.

Among existing model programs, Washington State has a Migrant Council that works with the whole family; the East Coast Migrant Head Start provides continuity of services; and overall, Head Start is an effective program because it is designed to serve the family as a unit.

# Chapter 4

## Presentation of Findings





# Chapter 4

## Presentation of Findings

On the final day of the Conference, the more than 700 participants came together to hear the findings of the Parent Work Groups. The findings were presented by three parent representatives, one for each of the topics discussed: awareness of and entry into health, education, and social service systems; participation in the systems; and transitions from one program to another within the systems. The parents prepared their presentations of the findings by working with the work group facilitators, recorders, and rapporteurs to determine a national consensus based upon the thorough written notes of the work group sessions. After the parent representatives presented the findings, the issues they raised were addressed by the Responder Panel, composed of directors of key Government agencies that provide services to families. This dual panel composed of the Parent Representatives and the Responder Panel was moderated by Rear Admiral Julia Plotnick, Chief Nurse of the U.S. Public Health Service.

## Parent Representatives<sup>1</sup>

### *Awareness of and Entry into Health, Education, and Social Service Systems*

#### **Sherlita Reeves**

*Parent Delegate from Arkansas*

Hi. She [Rear Admiral Plotnick] told you I'm from Clinton country. I live in a very rural part of Arkansas, and so that's the background I come from. I have two children. I have a 14-year-old who is normal, healthy, and looks like she's 18, and an 8-year-old who has spina bifida, a neuralgenic bladder, severely dislocated hips, club feet, hydrocephalus, and growth hormone deficiency and who must take injections daily.

HEALTHY CHILDREN Ready to Learn



I'm a multidegreed individual, and I think I'm well educated, but I have to tell you that *nothing* in my life prepared me for being the parent of a special needs child. But then, nothing prepared me for being the parent of a teenager, either. So, you know, you just have to learn as you go.

My 8-year-old daughter, who has spina bifida, has been involved in programs like Head Start, which was a blessing to my family. Presently she is on TEFRA,<sup>2</sup> which, as many of you may know, is the Katie Beckett waiver, and, again, that's been a Godsend to my family.

It can be very frustrating when you are working and trying to do good for your family, and just because

<sup>1</sup>The remarks of the Parent Representatives have been edited for clarity.

<sup>2</sup>The Tax Equity and Fiscal Responsibility Act (TEFRA), Public Law 97-248, enacted in 1982, allows States to amend their State Medicaid plans so that children with special health care needs under age 19 can receive benefits while living at home even though SSI rules require institutionalization under the eligibility criteria. Individual Katie Beckett waivers provide the same entitlements but were granted on a case-by-case basis, whereas TEFRA covers all children in the State who meet other eligibility criteria. Katie Beckett waivers were created in 1982 and phased out in 1984.

you are working and trying to do good, you don't have any more of an idea where to go for services than people who aren't working and well educated. I mean, just because you have a college degree, doesn't give you any great insight into how to deal with children. That's just something we all have to learn.

It's my task today to summarize to you the reports from the groups on awareness and entry, and I wish to let you know that I am speaking to you in a collaborative voice, and not as a single individual.

### **The Parents' Roles and Responsibilities**

The groups felt that the parents should first become informed about their own children's needs, and that they need to be informed about what services are available. It's very important to remember that knowledge is power. And we need to know what our rights as parents are.

Parents should be their children's advocates, and in order to do this, they must first have a belief in themselves. They've got to be able to meet their own needs in order to be equal partners with professionals and service providers. Parents should network with other parents because there is great strength in numbers, but we have to keep in mind that networking can be just one person with another person.

### **Issues of Concern**

There's just too much red tape and paperwork in systems that are not people oriented. It's very difficult to get into the systems, and once you get in, you don't want to stay. An example of this is problems with the Medicaid program. Medicaid says that they will pay for services for children who are indicated by screenings, but they are unwilling to pay providers enough money to make it worth their while. And the end result is the same: the child still gets no services.

The system is not set up to meet the needs of people whose first language is not English and who have a different culture. Their hours are inflexible for working people. If you've got a 9-to-5 job, a lot of times you can't take off work to get your child's immunizations without endangering your own job. That's a

problem. There are barriers for physically impaired people. There's a lack of transportation to providers, especially in remote rural areas. There is no accountability in the system, and if you have a problem, there is often no one to whom you can complain.

Our system fosters dependency. Generations are growing up on a welfare system, and it's becoming the only way of life that they know. In some cases, single parents making minimum wage cannot afford private health insurance to cover their children. And thus, in many cases, it's easier to be dependent on the system than it is to get a job. Welfare programs, such as AFDC, cause families problems; families are unable to get assistance a lot of times unless the father is willing to leave the home, thus breaking up the family.

There aren't enough tax dollars to go around. There aren't enough *dollars* to go around. Community programs are forced to compete for the same funds. This situation breaks up the community.

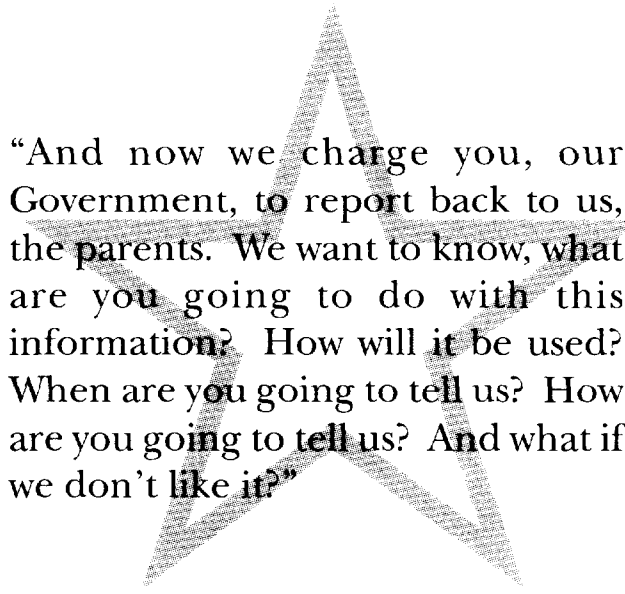
### **Solutions**

Now we get down to the meat of the problem, the reason we came. We feel that there should be school programs, starting in kindergarten and going through 12th grade, that develop social competencies, to prepare children on how to be effective parents and advocates for their own children later on in life. They could learn self esteem, self-confidence, problemsolving, decisionmaking, and how to get along with others.

We need to build support networks within the community—whatever that community may be for you, if it's your neighborhood, your workplace, etc. It may be people who have similar health concerns, or it might be your tribe.

There should be directories of resources available, locally, statewide, and nationally, with toll-free numbers for resource information. And there should be one-stop shopping for all mandated programs, such as Medicaid, WIC, or Food Stamps. And this should begin with a single application form, or as some people say, a "universal form."

Children need a comprehensive health care system from the time they are born. We need to provide



“And now we charge you, our Government, to report back to us, the parents. We want to know, what are you going to do with this information? How will it be used? When are you going to tell us? How are you going to tell us? And what if we don’t like it?”

prenatal care for everyone. We need early intervention. Public Law 99-457 is aimed at children 0 to 2 years of age. We need to target new parents. We need Head Start for children ages 3 to 5. Those are just some of the programs we felt had worked.

Parents should have a way of talking back to the system. Parents need a common ground with agencies, a respectful partnership that recognizes each other’s needs. This relationship is going to foster and encourage easy entry into the system. Parents need to build a method to evaluate the services they receive and hold service agencies accountable for the quality. There should be persons designated to respond to all complaints in a timely manner.

Children are our greatest natural resource and our future. There should be an all-out media campaign just as intense as the one for anti-smoking and AIDS awareness. It speaks very poorly of our country that we had laws to protect animals before we had laws to protect children.

We need to define our national health care system. This country needs to make up its mind. Is health care a right, or is it a privilege? Is insurance a right, or is that a privilege? There’s a parent here at this conference

today who is paying insurance premiums of \$1,000 a month. *How?* That’s \$12,000 dollars a year! How many families can afford that?

In closing, we’ve been asked to report to you, our Government, on everything that we’ve done in the last few days. And now we charge you, our Government, to report back to us, the parents. We want to know, what are you going to do with this information? How will it be used? When are you going to tell us? How are you going to tell us? And what if we don’t like it?

## **Participation in Health, Education, and Social Service Systems**

### **Ellie Valdez-Honeyman**

*Parent Delegate from Colorado*

I’m from Region 8 and the beautiful and mountain state of Colorado. I was born in the southern part of the state in a place called El Valle San Luis. It was there that I learned to speak Spanish with my grandparents, who were very special to me.

My husband, Mike, and I have six children. They range in age from 21 years—and I know I don’t look that old, but I am—down to 20 months old. We have three girls and three boys, and three of our children have disabilities. Currently, our home is also blessed with the presence of two grandparents, who are there for an extended stay. Two of our children with special needs are attending their home schools with support from special education. Our 5-year-old and our 20-month-old attend an integrated daycare program at a wonderful place in Denver, which has been our family’s Point of Light, called Laraden. There, our daughter Jamie, who’s 20 months old, also receives her therapeutic intervention.

We’re a complicated family, and we have some fairly complicated needs. We’ve had to challenge the system at all levels to get what we needed for our children. But right now I’m not here for them, and I’m not here for myself, or for my State, but I’m here to speak for parents all across our country who are represented by all of us at this conference. Every work group

addressed the areas of awareness, participation, and transition. And I'm going to try to speak about our collective thoughts on participation. I took the liberty and came up with a definition that I hope says what you thought participation means. Participation is being an integral and meaningful part of whatever it is that we need to be healthy families ready to live and learn.

In participating as families, we all identified some responsibilities and roles that we have. We need to provide for the needs of our children. That means giving them those things that can be seen and touched, like food, clothing, safety, health care, and quality time, which will in turn manifest itself in good self-esteem, confidence, or as one mom from the southeast said, [so] "They'll be emotionally and socially straight." After those immediate needs are met, we need to instill in them a spirituality that encourages values, morals, and respect for themselves and for others.

We need to be advocates. We need to be advocates for our children. We must get their needs met first, and after we do that, we can become advocates for other families who are just starting out, or who are stuck. And finally, we can advocate for the system components that

work for us. We need to develop partnerships with systems. We must become partners with the systems, and becoming partners means there's an equal status and respect of input, as well as capability.

Parent to parent—that can mean a lot of things. But, parents, I suggest that we need each other. No matter whether we're a stepparent, foster parent, single parent, birth parent, adoptive parent, grandparent—we need each other. And we can help each other by supporting, mentoring, role modeling, or whatever it is that links us together. We need each other.

We're responsible for community education. We must become involved in our communities, because by our presence, we'll educate about the benefits of integration and inclusion and we'll get beyond just cultural awareness and cultural sensitivity. We'll all become culturally competent. In other words, we won't just serve tortillas and peanut butter around Cinco de Mayo, but we'll have all our forms available in the languages that the people speak. We'll understand that when a Native American mom doesn't make eye contact, it's out of respect, not disrespect. We can go on and on about those areas of competency and what that means.

Regarding these parents' roles, we identified some issues of concern. There were many, but the ones that came through loud and clear were the stigma of receiving services, the stigma around being poor, a circumstance over which babies have no control. One of us here identified "a national psychology" that stigmatizes you if you are a recipient of certain Government benefits. One mom described her embarrassment at the checkout when she overheard someone make a comment about her purchase of cookies with her Food Stamps. She was almost in tears when she said, "Doesn't every child deserve a cookie now and then?"

Ironically, we have families who can't get those benefits, because they make a few dollars over the maximum. A parent from New Hampshire says she can't afford to get a job, because she'll lose income and her health care. Eligibility is the barrier. Eligibility for services should not be just income-based. We can't forget those families who should be eligible because they have children with overwhelming needs.



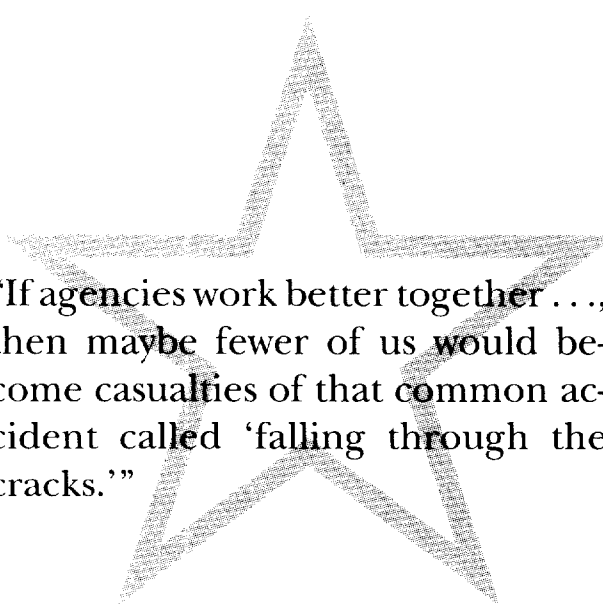
There were lots of barriers to participation in services, programs, and support. But some of the ones that kept getting mentioned were language, and not just non-English, but language full of complexity and jargon. “System language” that only a bureaucrat can understand, and that *they* sometimes can’t even translate, is also a barrier.

Transportation is a barrier in rural areas. There aren’t enough services, and sometimes you have to travel far to get what you need. In large urban areas, lack of public transportation can keep you away too.

Inflexibility is also a barrier. We need flexibility from our employers to get to the services. We need services to be available at flexible hours and in flexible places. Families need to be able to identify who their community and family are. A big barrier sometimes develops when the systems try to define family and community.

Bureaucracy is complexity, and often the bureaucrats don’t understand the system. Paperwork is complicated. One mom in the northeast told us how she was eligible for Medicaid and she had her card, but she couldn’t find a doctor who would see her. Doctors are often leery of Medicaid patients, not just because of the low reimbursement rate, but because of the paperwork and the time involved in getting their money.

Being the proactive and sensible people that we parents are, we identified some solutions, and we put them into two categories. The first one was local initiatives. We identified that we need flexibility in service delivery. A variety of hours and days when the services are available would really help us. Our providers need flex time, if necessary. Our moms and dads who work need support after 5:00 p.m. and sometimes on weekends. We need consistency in funding. We want to be sure that the services that we need will be there tomorrow. Locally based services and support need to be available and close to home. We want our children with disabilities to go to school with their brothers and sisters and neighbors. We want all children to get a fair shot at education, not based on the income—or lack of it—of their parents. We have to foster self-esteem. The services, supports, and benefits



“If agencies work better together . . . , then maybe fewer of us would become casualties of that common accident called ‘falling through the cracks.’”

should be viewed in ways that are meant to help families to become enabled and in which empowerment is facilitated. We all have the potential for empowerment. More support should go to programs that make families rejoice in the success of being self-sufficient.

As parents, we accept some responsibility. We think that all parents have to be involved, as budget planners, policymakers, and partners in decisionmaking. We saw interagency collaboration as a key solution. Good services will result from good interagency collaboration, and once again, the collaboration should include parents—not as tokens but as real participants, who are respected and maybe even paid for their expertise. If agencies work better together (or, as a bureaucrat friend of mine from Denver said, “smarter, not harder”), then maybe fewer of us would become casualties of that common accident called “falling through the cracks.”

The second category is Federal initiatives. Our *compañeros* in Region 2 actually put together an initiative for a partnership across all Federal agencies that would include families and agencies from local levels. This partnership would be a formal structure that would create a standard in which service systems welcome and embrace families and use proven models that work, such as Head Start. The principles outlined in the plan would be embodied in the design, delivery,

and evaluation of services. The philosophy must include family-centered, comprehensive, and accountable service and support. And again parents must be included as equal partners.

Dr. Novello, you issued us a challenge when we came here, and you've already heard one challenge. We're issuing another one. We as parents voted last night, and we decided that, from Washington, you should lead that initiative.

I want to thank Rosa Palacios, a parent who supported me last night through the long process of putting all these collective thoughts together, and I just want to share with you something that I learned at this conference. I saw, and I see, a real beauty in the diversity here, and we need to celebrate in that diversity. I also felt a power in collectiveness, and I think we need to harness this collective power. We need to identify those areas that are important to all of us, such as family, health care, and education, and we need to unite as parents—all kinds of parents—to make our families healthier and happier, to make health care accessible, and to make education more than just an academic experience, but an experience in living. To do this I suggest the leadership must come from all of us.

## **Transitions** *Through Health, Education, and Social Service Systems*

### **Larry Bell**

*Parent Delegate from Delaware*

Being up here makes me pretty nervous, especially in following these very competent young ladies who went before me. I want to take this time to thank Dr. Novello, and all the parents that were here, and all those people that kept me up all night last night trying to put this together. And especially for the parents that were in Region 3, which is the group that I was in, for their support. It is an honor to have been chosen to stand and represent you.

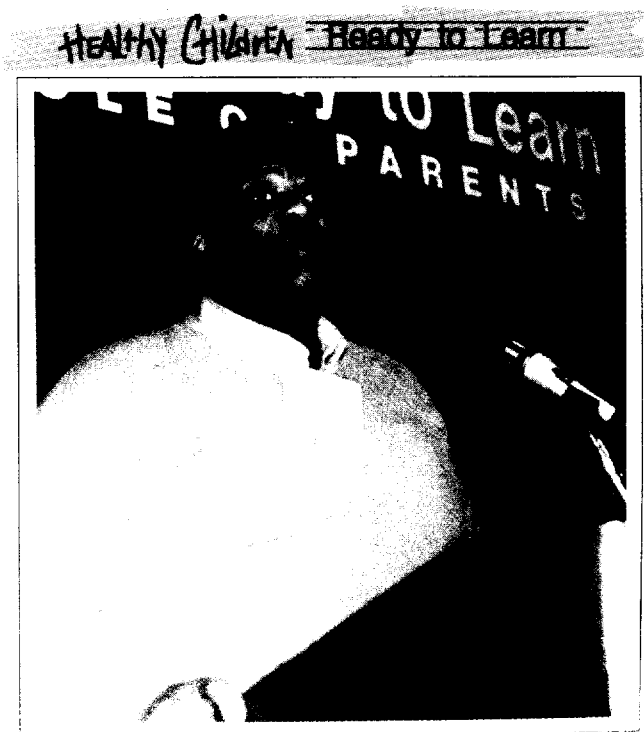
I was waiting, and I saw my wife come in—are you here, somewhere? Yes, okay, I feel better now. They were calling me this morning wondering where I was, and I

came down, and I had all these people (I guess security people) with walkie-talkies calling and yelling, “They’re coming through.” It made me feel good as an African-American male to have all that security and not be on my way to jail.

My name is Larry Bell, and I’m from Delaware. I have five children and three grandchildren. I’m a second-generation Head Start parent. I was involved with Head Start when my children were in Head Start, and now I have custody of one of my grandchildren who’s involved in Head Start, and that’s how I ended up being involved in this process today.

The purpose of my presentation is to bring together all of the work that the parents have put in so diligently over these past 3 days and talk about issues of awareness, participation, and transition. And my topic is going to be transition.

First, I want to share a little story. I heard a minister friend of mine—and by the way, I forgot to tell people that I was a minister and was going to be passing the collection plate in a few minutes—I heard a minister friend tell a story of how every time he went home and they sat down to dinner, they always had squash. He hates squash. Every



time they passed the food around, when it came to him, he would pass it on to the next person, and his mother would say, “Boy, what’s wrong with you? You know you don’t pass food without taking some and putting on it your plate!” He would say, “But Mom, I hate squash!” She would take the squash and proceed to put more on his plate than he would have if he had done it himself. He would say, “But Mom, why are you making me eat this? I hate squash.” (And he’s a grown man.) And his mother would reply, “Because it’s good for you.” The point is this: the information that we as parents are presenting to you, especially the legislators, is the truth. Some of that truth that you hear will be “squash truth.” It will be truth that you may not like to hear; it may not feel good, but it will be good for you. And throughout my topic here, we’ll be covering the issues and roles and responsibilities of parents; we’ll be dealing with the problems, issues, and concerns as well as solutions. And I kind of combined them together.

The thing that I want to leave and impress on all of us before we leave here is that all of us have a responsibility when this Conference is over. People are asking, “What’s going to happen with the information? Is this just to be another time that we come together and share information and nothing happens with it?” It might be, but knowing from what I’ve seen, the time that I spent with and around Dr. Novello, I don’t believe that’s going to be the case.

But all of us, when it comes to working with problems, solutions, and transitions, have a responsibility when we leave here to go back to our communities and meet with various agency officials to begin to talk, share ideas, and discuss the roles of parents and the roles of people involved in the system. We all have a responsibility when it comes to the transition of our children. Our charge to our parent delegates is to go back to your communities and meet with the officials of whatever system or systems that affect or impact on your children. Sit down and define those roles.

When we talked about transition, we came up with nine major issues. And the first one is that parents need to participate in the transitional process. Parents need to be aware of their children’s needs, including health

needs and special equipment needs. They should be encouraged to articulate those needs to the systems in which they will be involved. Parents need to be prepared for and about the transitional process. But we need to remember that transition really begins with the transition of the parent, to prepare children for the transition—to do things like introducing them to new people, taking them on a tour of the school, finding out the daily routine, and talking to our children about that process. To prepare our children for transitions such as having their parents at these conferences that involve their children, people need to talk with their kids about the change as soon as they know that it’s going to happen.

We also decided that it would be very helpful to develop a resource manual, information that would be available and accessible to the parents so that, when they move through different systems, they would have a source with the names and numbers and contact people. Then, when other needs arise in the future, they will have something in their hands so that they can contact somebody to have those needs addressed.

We felt that parents also should be encouraged to be good recordkeepers, to have copies of all their children’s records so that as they move through the transitions, if the system fails to make sure that information gets moved on or passed on to the next system, the parents at least have a copy of that information to make sure that it gets passed on.

We thought that parents needed to demand respect for themselves and for their children and that the systems that they’re involved in need to respect them and recognize that parents are professionals too. We felt that one of the other things that would help in the transitional process is for the systems and the parents to sit down together and share and clarify their roles in who’s going to be responsible for what.

We also need to improve communication between systems. Improving communications would make for smoother transitions; it would help decrease turf wars, avoid duplication of services, and help to promote the continuity of services.

We felt that program materials need to be written in the language of the parents, to take into consideration

the languages of non-English-speaking people. Also, we suggest using picture books for those parents who might be illiterate and being sensitive to language that doesn't always translate exactly into English. Many of the Native American terms don't always compare when they are translated, and we need to be sensitive to those kinds of things.

Successful transition depends on having everyone involved to learn to trust each other and the systems that impact upon their lives and the lives of their children. We want you to know that this takes work on both parts to develop that kind of trust. We want a system that we're involved with to avoid technical jargon and using terms that we don't understand. When you sit down to work with parents to develop an IEP, make sure that you speak in terms that the parents understand, and make sure that the parents are aware that they don't have to sign an IEP if they disagree with it.

Another area of concern was that programs and staff must be culturally sensitive and relevant. Systems need to see parents as the prime educators of their

children and especially educators of their own cultural heritage. Programs need to be aware of and address issues of racism that occur during transition—or any time that it surfaces directly or indirectly. Remember that the sensitivity in this area goes beyond just ethnicity, but also should take into account social and financial status and spirituality issues. Remember to label cans, and not kids.

Also, we must focus and work on developing parental and child self-esteem. We want to focus on the children, but when you're working with the children, remember that parents need self-esteem too, and those issues need to be addressed. Parents must be good role models for their children and be good role models throughout the transitional process. Sometimes this means finding a good role model for the parent.

One of the responsibilities of parents is to love their children, but we know that before you can love other people you first have to love yourself. Parents must learn to be able to feel good about themselves before they can help their children feel good about

