

# Chapter 3

## Parents Speak Out: Summary of Parent Work Groups



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HEALTHY CHILDREN



--- Ready to Learn ---

### SUMMARY OF PARENT WORK GROUPS

**D**uring the Conference, the State Parent Delegates attended work groups to which they were assigned according to the geographical regions in which they live. Native American and Migrant parents could choose to attend the regional work groups or separate work groups, which were established to ensure that their special needs or issues were not lost. In all the work groups, roundtable discussions were held to discuss three topics representing stages of families' involvement with health, education, and social service systems: awareness of and entry into the systems, participation in the systems, and transitions from one program to another as families move through the systems. In their discussions, the parents examined three main questions related to these stages: (1) What is my role as a parent in this stage of working through and with the systems? (2) What are the barriers or other issues I face in this stage? (3) What are some solutions to these problems, and what are some existing model programs that incorporate some of these recommended solutions?

This section details the issues raised by the parents. First, a summary of the national consensus, broken down by topic, is given. The national consensus summary contains issues raised by several of the work groups and upon which they were in agreement. Next are summaries of the comments made by each work group (regional, Native American, and Migrant). To avoid repetition, these descriptions may not include issues contained in the national consensus. Their purpose is to highlight the issues that were of particular concern to the specific work group rather than to provide an exhaustive list of issues discussed in each work group.



# National Consensus

## Findings at a Glance

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

#### **Roles and Responsibilities of Parents**

- ★ Identify their children's needs
- ★ Interact and communicate with their children on a daily basis
- ★ Consider themselves equal partners with professionals who also care for their children
- ★ Participate in networks and support groups

#### **Barriers and Issues of Concern**

- ★ Confusion about the systems due to limited available information or contradictory information
- ★ Too much "red tape"
- ★ Cultural insensitivity and communication barriers
- ★ Poor attitudes and intimidating behavior of service providers
- ★ Poor pay and lack of incentives for providers to accept Medicaid
- ★ Inflexible hours of programs, clinics, etc.
- ★ Transportation problems/inconvenient locations of service facilities
- ★ Inflexible criteria for eligibility to receive services
- ★ Lack of accountability within the systems
- ★ Inadequate funding of needed services

#### **Solutions**

- ★ Universal application form to apply for an array of services, such as WIC, Head Start, Food Stamps, etc.
- ★ One-stop shopping, with assigned resource coordinator for each family and provision of service directories, including toll-free hotlines
- ★ Flexibility in criteria to establish eligibility to receive services
- ★ Convenient operating hours for programs and facilities
- ★ Elementary school curricula in social competency and parenting skills
- ★ Funding for support groups for families
- ★ Mechanisms within the systems for establishing accountability and for halting complaints
- ★ Rotation of service-provider staff to prevent employee burnout
- ★ An awareness campaign to promote the importance of healthy children
- ★ Development of a national health care policy

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

#### **Roles and Responsibilities of Parents**

- ★ Become empowered and become role models for their children and other parents
- ★ Serve as advocates for their children, for other parents in the systems, and for the programs that provide services to them
- ★ Be involved in program activities and work with service providers in meeting their children's needs

- ★ Train service providers in their culture and unique family characteristics
- ★ Be involved in program decisionmaking and in evaluating services

### **Barriers and Issues of Concern**

- ★ Bureaucracy, inflexible hours, and transportation problems
- ★ Gaps in services
- ★ Lack of coordination among services
- ★ Lack of a family-centered philosophy
- ★ Insensitivity not only of service providers but of the public at large
- ★ Lack of incentives for families to become independent
- ★ Rigid eligibility requirements
- ★ Inequities in funding for education
- ★ Frustration with the systems
- ★ Hesitation in confronting the systems
- ★ Need for support groups

### **Solutions**

- ★ Training in parenting skills, beginning as early as elementary school
- ★ Improved communications among service agencies and central community resource clearinghouses (one-stop shopping)
- ★ Paid positions for parents on boards that oversee programs
- ★ Employment policies that support families, such as family leave
- ★ Secure and increased funding for programs
- ★ Media campaign to improve public opinion of families receiving services
- ★ Election of government officials who support families
- ★ Expansion or adaptation of model programs to reach more communities and families

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

### **Roles and Responsibilities of Parents**

- ★ Be active participants in the transition process
- ★ Be good recordkeepers
- ★ Demand respect and develop self-esteem for themselves and their children
- ★ Be a good role model for their children and for other parents
- ★ Define the role of parents for professionals in the systems

### **Barriers Families Face During Transitions**

- ★ Lack of communication among programs and the need for one-stop shopping
- ★ Failure to receive copies of children's records; records that contain technical jargon or that are not translated into parent's native language
- ★ Lack of sensitivity
- ★ Lack of consistency in parental involvement across programs
- ★ Need for support groups
- ★ Too much paperwork
- ★ Transportation problems
- ★ Inflexible programs and facilities
- ★ Lack of employment policies that support families
- ★ Abolishment of programs because of unstable funding

### **Solutions**

- ★ Toll-free hotlines and resource directories
- ★ Sensitivity training for service-provider staff
- ★ Mentoring of new parents in the programs by system veterans
- ★ Guidance for parents provided by doctors, hospitals, and other service providers
- ★ One-stop shopping and assignment of one case-worker per family for all programs
- ★ Reform of eligibility requirements to consider net pay, examine hardship conditions, and provide a safety net
- ★ Legislative action, such as family leave policies
- ★ Assertiveness training for children by their parent

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

The parents willingly accept their responsibility as the primary provider of their children's needs. However, they also acknowledged that every family needs help occasionally. Federal, State, and local programs can support informed parents who enroll their children into these programs. Unfortunately, lack of information, bureaucracy, and inflexibility in service provision prevent many families from benefitting from these programs. The parents maintained that programs must be coordinated under the one-stop-shopping approach to supply flexible and accountable service.

### **Roles and Responsibilities of Parents**

The delegates recognized that they must first identify their children's needs. Children need to be immunized, given a proper diet, nurtured, taught self-respect and respect of others, taught learning skills, provided

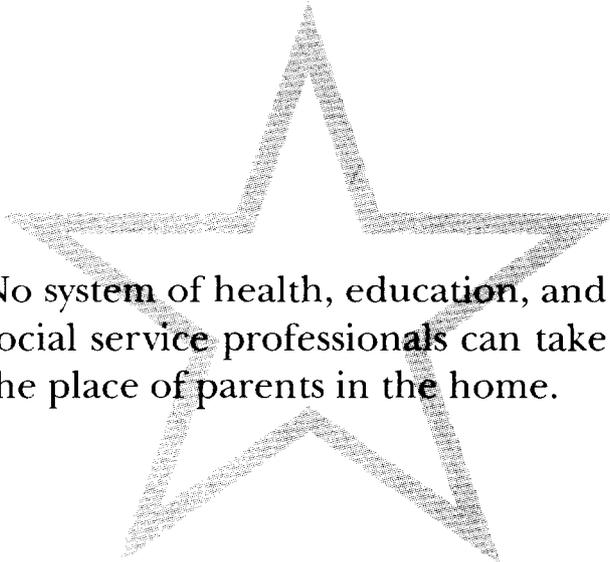
professionals and other care providers and be recognized as such. Parents who know their children's health needs and risks and the services available to support them make self-confident parents who can work effectively with care providers. While respecting the judgments of professionals, parents should not surrender the decisionmaking to them; when professionals give advice that seems questionable, parents should trust their own instincts enough to seek second opinions. As advocates for their children, parents should be assertive and persistent but should not forget to be diplomatic. The way they interact with care providers will influence how their own children behave toward others. Good partnerships are respectful partnerships.

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with a safe, stable home environment—the list is long, covering the full range of physical, emotional, and spiritual development. No system of health, education, and social service professionals can take the place of parents in the home. Parents must take the time and effort to know their children. Federal, State, and local programs can serve only a supporting role as parents struggle to raise healthy children.

Daily interaction and communication with children is key. Good parents listen to their children, not only when they complain or are sick but also at other times. Parents with special needs children must make an additional effort to maintain balance within the family and to devote attention to healthy siblings. All children, however, can benefit from existing Federal, State, and local programs, and parents must take the second step of finding out what the programs are and what they have to offer toward meeting their children's needs. There is no substitute for the well-informed parent.

The delegates maintained that parents should consider themselves partners on equal footing with



**No system of health, education, and social service professionals can take the place of parents in the home.**

Finally, the delegates agreed that networks and support groups are a tremendous asset. Parent networks can provide information, moral support, and hands-on care, and can make up for some—though certainly not all—of the failures of the present health care systems. Networks can help parents at all stages of their children's health care, but most of all in the entry stage, as they make their first tentative and sometimes confused steps into the programs. When an individual family questions a professional opinion, networks can supply alternative sources of information; when the family doesn't know where to turn

or what step to take next, networks can point the way. Networks allow parents to draw from the shared experiences of other parents and work together toward common goals. Not all parents entering the programs know their rights, and networks give them the opportunity to learn and exercise their rights in an unthreatening environment. Networks are effective in this way because they teach by example.

Networks can also help parents learn their responsibilities. Not all parents are responsible parents. While it is important that parents raise their children as they see fit, some fail to recognize that their children have special needs. The children may be physically healthy but have learning disabilities or behavioral or emotional disorders, and their needs may pass unnoticed. The parents may have alcohol and other drug problems or problems that lead to child neglect or abuse. These parents may deny that problems exist. They may be reluctant to seek help because they believe it is shameful to do so. Professional health care providers can intervene in such cases. However, professionals are often perceived as threatening and, as a rule, are less effective than parent networks in these especially difficult cases. Troubled parents are more likely to listen to other parents and to perceive them as partners rather than as authority figures. The other parents can, in turn, seek guidance from the rest of the network as it shepherds the family into the health care systems.

### **Barriers and Issues of Concern**

The most often cited problem of parents being aware of and entering programs was confusion about the systems. To many parents, the systems seem designed to discourage them from the start: To withhold information and frighten them away with paperwork. No single source of information on the many available resources exists, and information provided is often contradictory. In addition, many employees of the programs don't even know how the systems work, nor do they know how to access the information that can help parents find their way.

The amount of red tape is enormous; application forms are long and complicated. To make matters

worse, different agencies have different application forms, and parents are forced to repeat the same complicated procedures as they try to move from one agency to another. As one parent stated, "The paperwork doesn't flow."

In addition, application forms make no allowances for the diversity of applicants. Parents who are not native English speakers often have great difficulty trying to make sense of the forms. Even fully fluent English speakers make this same complaint. No allowances are made for cultural differences or for the communication styles of minorities. Alternative services for the blind and the hearing impaired are also lacking.

Many delegates complained that the attitudes and behavior of social service workers and health care providers can be patronizing, unfriendly, intimidating, and sometimes even abusive. They believed that a great many social service workers suffer from employee burn-out. Workers are not sensitized or properly trained, and they therefore bring their prejudices to the workplace. Parents entering the programs feel this most strongly, while those at later stages come to expect a certain degree of mistreatment as part of the price they must pay in exchange for services. "It's hard to get into the system, and once you get in, you don't want to stay," stated one delegate. But their needs force the parents to stay, with the result that they come to feel as trapped by the systems as by the needs that brought them to seek help in the first place.

As for health care providers, their attitudes and behavior tend to reflect their own unhappiness about how poorly they are paid for the services they provide. Medicaid, for example, pays providers so little that they have no incentive to take Medicaid patients. As a result, the patients often receive inferior care or are refused care outright. Ultimately, the patients are the ones who suffer from inadequately funded programs that fail to deliver on their promises. The health care centers themselves often present a variety of physical barriers to disabled children.

Another concern was the lack of flexibility in office hours. Social service and health care providers



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who hold 9-to-5 office hours are making no allowances for working parents. The working parent who has to leave work—losing a morning, an afternoon, sometimes a whole day in the process—to meet these inflexible hours may be at risk of losing his or her job. This situation, in turn, may put the child at risk of forgoing important preventive medical services such as immunizations and well-child checkups.

Transportation is a related problem. Parents often have to take long hours away from their jobs because they have to travel long distances to their appointments, and they often have to rely on either public transportation or help from friends. This problem is particularly acute in remote, rural areas.

The delegates expressed unanimous dissatisfaction with eligibility criteria. The criteria are artificial and inflexible. They do not reflect real income—net income, after taxes—and applicants can be denied entry into programs if their income exceeds the criteria by as little as a few dollars. A family may meet the criteria one year, only to be disqualified the next because of a slight rise in

income. While the eligibility criteria are meant to prevent abuses, the criteria themselves often foster dependency. In many cases, a family can benefit in the short run—qualify for Food Stamps, for example—if one of the parents quits a job so as not to exceed the eligibility criteria. Quitting a job can actually mean more food on the table. Under some welfare programs, a family can qualify only if the father leaves home. “You learn to play the game,” one parent said. Parents take these steps, not because they are lazy or cynical but because they have immediate needs and feel they have no other choice. However, the choices they make often mean that dependence on welfare programs is handed down from generation to generation.

Parents who try to make this point with social service workers feel even more frustrated. They face a bureaucracy from the moment they enter a program, and they either adapt to the bureaucracy or go without services. If they feel they are mistreated, they have no one to turn to within the systems. They see a general lack of accountability and are often afraid that if they

protest, they will be denied services or subjected to further mistreatment.

Inadequate funds are an underlying problem for all programs. Because there are simply not enough dollars to go around, programs serving the same communities are forced to compete for the same dollars. This competition creates divisions within communities, and the rifts are often felt in the parents' networks. Parents will naturally fight for the children, but when they are forced to fight other parents, the real losers are the children.

### **Solutions to Promote Awareness of and Entry into Systems**

First among the proposed solutions was a universal or near-universal application form for all services, with consistent eligibility criteria. The form should be easy to read. Alternate versions of the same form should be made available to parents who are not native English speakers. Special arrangements should be made for the blind, the hearing impaired, and applicants with low literacy levels.

There should be a single point of entry for all services, i.e., one-stop shopping. When families enter the bureaucratic maze, they should be able to consult a single source for comprehensive information on available services and referrals. A resource coordinator should be assigned to each family, and the family should be provided with local, State, and national directories of available services. Toll-free hotlines for resource information would be a useful supplement.

Eligibility criteria need to be more flexible. The criteria should be based on real (net) income. Inflexible criteria often foster dependence on the systems, as parents quit jobs or avoid seeking employment and fathers leave households so that families can meet eligibility criteria. Greater flexibility will promote self-help.

Agencies must also have flexible working hours—not just 9 to 5—in support of working parents. Many parents risk losing their jobs if they have to take time off from work to meet appointments with care providers.

Programs should be instituted in elementary schools to develop social competency and parenting skills and to

help train children to be effective parents and advocates for their own children someday. The characteristics taught should include self-esteem, problem-solving and decisionmaking skills, and respect for others.

Funds should be made available to help create and maintain support groups. Support groups are popular: they encourage parents to take a more active role in raising their children; they develop parenting skills; and, because they promote self-help, they can actually lighten the burden of social service systems. As one parent stated, "The best program is the program that doesn't cost anything," in other words, that encourages independence. Support groups are the closest known approximation to that ideal program. They can be developed at the neighborhood level, at the workplace, at schools, or within the tribe, and they can be tailored to any number of specific needs.

Parents need a way to talk back to the systems. Parents are partners with service providers, and the true beneficiaries are the children; when the partnership breaks down, the children pay the price. Parents should be treated compassionately and with respect. A mechanism should exist by which parents can submit evaluations of the services they receive and register complaints when necessary. Complaints should be addressed in a timely manner. The bureaucracy must be more accountable, and accountability must be on site to be effective. Parents who have been recipients of programs should serve on agency advisory boards.

Many delegates expressed the belief that employee burnout is responsible for much of the rude treatment parents receive. The delegates suggested that rotating employees to different posts within agencies could help prevent burnout and would certainly result in better informed employees who can then pass their knowledge on to needy families.

An all-out effort needs to be made to raise public awareness as to the importance of healthy children. Antismoking and AIDS awareness campaigns have proven effective; children should be the next focus.

Together with a media campaign on children as an investment in the future, this country should initiate an energetic debate on our national health care policy.

Is health care a right or a privilege? Is health insurance a right or a privilege? We cannot expect to move forward on particular solutions without defining our values and goals in specific, practical terms.

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

As families participate in health, education, and social service systems, parents must seek education for themselves and become empowered, the delegates maintained, so that they can become role models for their children and for other parents whose families need services. Furthermore, programs should offer incentives for parents to become empowered and for their families to become independent. Programs need to become family centered, and parents need to be involved in program decisionmaking to keep programs focused on providing quality service to meet families' needs.

### **Roles and Responsibilities of Parents**

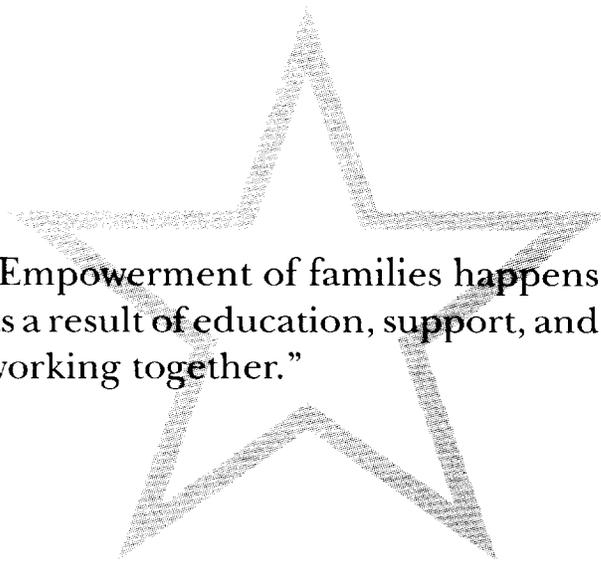
The delegates agreed unanimously that the parents'

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primary role of nurturing their children does not change as their families participate in health, education, and social service systems. Parents of children who receive services do not relinquish their role as the primary advocates for their children and as the parties responsible for ensuring that their children's needs are met. On the contrary, the delegates expressed that participation in programs brings added responsibilities to the parents. The delegates contended that parents in families receiving services have an even greater responsibility to become empowered themselves so that they can empower their families. They stressed that parents must seek education, when necessary, and good mental health; they stated emphatically that parents have the responsibility to be "emotionally and socially straight." As parents become empowered, they become role models, not only for their children but for other parents in the community.

An important function of parents whose children receive services in serving as role models is to reach out to other families and enlist them into the programs. When new families are enlisted, declared the delegates, these parents have a responsibility to help orient the new families in the programs by providing them with information and offering their support. In this way, parents serve a dual advocacy role—for new parents, by offering their support, and for the programs, by publicizing their services and being committed to them. This commitment may involve lobbying for endangered programs. As parents serve as advocates and network with other parents, they can build community support for families. As one delegate stated, "Empowerment of families happens as a result of education, support, and working together."

Working together, the parents insisted, also means working with the service providers. Parents can support the efforts of professionals working with their children by being involved with the programs' activities and offering supplemental exercises at home. Parents should ask teachers or other care givers for activities that they can use at home. Working together for the children's benefit can build trust among professionals and parents, with the result that service providers may begin to view parents in the manner that they so fervently desire, i.e., as experts where their children



**"Empowerment of families happens as a result of education, support, and working together."**

are concerned and as respected partners in providing for their health and education.

Parents also have a responsibility to train service providers in the culture and unique characteristics of the families they serve. Only the parents can educate the community about the special problems of minority families, for instance. Programs must understand the communities they serve to adequately meet their needs.

Repeatedly, the delegates insisted that, as respected partners, they should have a voice in the programs that serve their families. They contended that, because they have a vested interest in the quality of service, they should be involved in all aspects of the programs, from program design to budgets and hiring decisions. The parents' role should extend from planning and implementing programs to evaluating them and their services. After all, the quality of services affects the parents directly; they are the first to know when needs are not being met.

### **Barriers to Participation and Issues of Concern**

On the topic of participation in health, education, and social service systems, parents reiterated many of the complaints that they had expressed concerning awareness of and entry into the systems. The frustration with the systems does not end when families become involved, they stated, citing the same difficulties in obtaining information, inflexibility in hours and services, transportation problems, and language barriers. Nor does the amount of "red tape" decrease once a family is participating in the programs. Stated one delegate, "Bureaucracy often discourages participation."

The delegates were also concerned about gaps in services, which service providers often do not address directly but instead "pass the buck," sending the family from one provider to another in search of the needed service. The supply of services is often inadequate to meet the demand, resulting in long waiting lists or the use of quotas. For instance, the lack of affordable daycare was a problem cited by many delegates.

The delegates attributed many of these problems to two principal factors: lack of coordination among programs and the absence of a family-centered philosophy.

Coordination and collaboration among programs would facilitate the identification of gaps in services, as well as duplication, so that resources could be used more efficiently to meet the needs of clients. The implementation of a family-centered philosophy would ensure that programs would provide parents with the necessary information, would have flexible hours, would be conveniently located, and would consider their families' cultural and language backgrounds, not only in their printed materials but also in their policies and procedures. The delegates also stated that leadership is lacking at the Federal and State levels, resulting in a resistance to such changes in the systems.

The insensitive attitudes of service providers often extend to the public, the delegates maintained, leading to a "national psychology" that looks down on parents receiving services. Delegates shared the embarrassment of themselves and friends created by comments that other customers in checkout lines make regarding their use of Food Stamps. The delegates want the general public to know that parents whose families receive services care about their children and that their misfortunes can happen to anyone. "Our country is not segmented into welfare recipients and the rest of us," one parent insisted. In fact, most people in this country benefit from some kind of public funding, for example, farm subsidies.

As we improve our attitude toward families receiving services, the parents countered, we must not let them become apathetic or complacent, with the result that they are dependent on the systems. The delegates repeatedly said that the systems need to offer incentives to parents to become independent. Often, they said, programs provide a quick fix for crisis situations without addressing the underlying causes. True healing cannot begin, they said, until the systems provide a holistic approach to treating family problems. As one parent said, "There is a sense of futility on the part of some families, a lost sense of what they could be reaching for and what they might achieve."

Some delegates complained that middle-class children often are "squeezed out" or "fall through the cracks" between programs because the families are not

eligible for services; yet the parents cannot afford to provide for more than the child's basic needs. Health care, for instance, was a major concern; the delegates reiterated that every family has a right to adequate health care. Once again, the parents criticized the rigid eligibility requirements.

This situation also extends to education, they maintained. They contended that inequities in funding in the local school districts automatically precludes "equal education for all," and middle-class children often are not eligible for special educational programs. They urged that these funding inequities should be addressed.

Finally, the parents expressed again their frustration in confronting the systems to achieve positive changes. Even parents who are actively participating in systems hesitate to make waves. Said one parent, "If you act assertively, you are isolated." They reiterated the need for family support groups and funding to organize them.

All of these problems can be overwhelming for

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parents at times. One delegate summed up this sentiment with the following remark: "The children are our future, and it's scary."

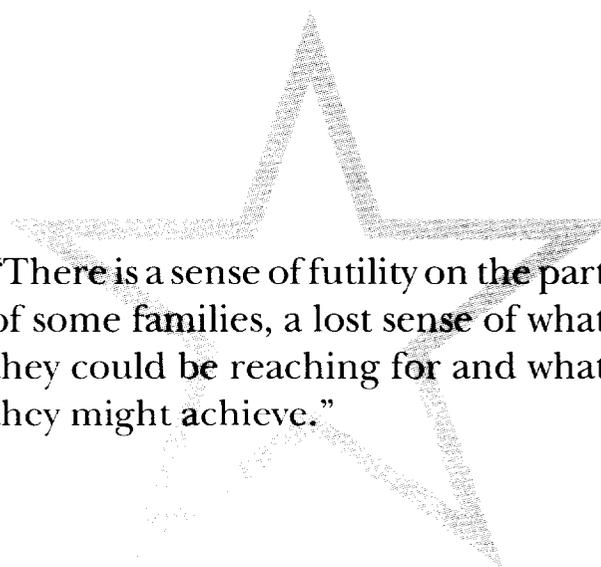
### **Solutions to Facilitate Participation**

Although the problems may seem overwhelming, they are not insurmountable, the parents stated emphatically. They recommended taking steps in the following areas to begin to break down the barriers to producing healthy children ready to learn.

First, the parents advocated that training in parenting skills should begin early, before a youngster becomes a parent herself or himself. They pointed out that our young people receive limited training, at best, for their most important role. Most of us follow the parenting styles of our own parents, but not everyone is fortunate enough to have loving and nurturing parents. Early training in parenting skills is imperative.

The parents stressed that, for parents who need services, improved communications among service agen-

cies would solve many problems. Improved communications would facilitate entry into and participation in programs because service providers would be able to guide families to the most appropriate program to meet their needs. The delegates recommended central community resource clearinghouses. Such clearinghouses should be staffed with culturally sensitive employees, should provide the paperwork to apply for services (preferably through the use of the universal application form), and offer flexible hours. Such a facility would lead to better coordinated services and a reduction of gaps and duplication in services. It would



**"There is a sense of futility on the part of some families, a lost sense of what they could be reaching for and what they might achieve."**

be a first step toward implementing a one-stop shopping approach. In addition, the delegates recommended that resource hotlines be established, that directories of services be published, and that each community's telephone directory include a directory of local services and resources.

To move toward a family-centered philosophy in the systems, the delegates recommended that parents be elected or appointed to the boards that oversee programs. Through their positions on the boards, the parents could offer input, not only in planning but also in evaluating the programs that serve them. Parent input would keep the programs focused on the bottom line: providing quality service to meet the needs of

families. The delegates added that parents should be compensated for their work and the expertise they would bring to the planning and evaluation processes. Without compensation, they asserted, the parents would find it more difficult to gain the recognition they deserve as respected partners.

Employers also need to recognize the importance of families and develop policies accordingly. The delegates expressed a need for flex-time so that they can more easily attend to family matters. The work groups universally endorsed the passage of a family leave act. They also recommended that employers support daycare centers for their employees.

Secure and increased funding for programs to ensure their continued existence would also improve participation in the systems, the delegates maintained. Funding is particularly important for parent support groups. In addition, the delegates recommended that funding mechanisms for education be changed. Furthermore, they recommended overall reform of the educational system.

The delegates urged that a “national psychology” be developed acknowledging that all children and families have the right to certain basic supports for their health and well-being. This attitude can be achieved through the media. One group maintained that the Surgeon General’s Office “has the power” to change public opinion through an advertising and public relations campaign stressing this concept. Television spots could show a respectful approach to families applying for services.

Another aspect of changing the national attitude is to elect officials who actively support families. The delegates urged that Americans become involved politically. If we are to solve many of the problems facing our families, they said, we must have committed leaders.

Finally, the delegates asserted that we have model programs that show us what works. We should adapt local model programs to other communities and expand model programs for special needs children to fit all children. Elements of the most cited model program, Head Start, could be incorporated in the primary grades, for instance.

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

All parents and children experience transitions. The Parent Work Groups agreed that parents, agency officials, and community people all have roles and responsibilities in the successful transition of children through health, education, and social service programs. Being ready to learn, they said, is more than making children ready for schools; it’s also making schools ready for children. They concluded with what they called the “rule of the three C’s,” which they said drives successful transitions: Consistency, continuity, and coordination of services are all necessary to promoting healthy children—and families—ready to learn.

### **Roles and Responsibilities of Parents During Transitions**

As they discussed parental roles and responsibilities in transition, the 12 work groups centered their thoughts on the following question: How do we, as parents,

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ensure a smooth transition from birth through infancy to early childhood to being healthy and ready to learn for entering school? One response was sounded repeatedly: Parents need to be active participants in the transition process because they are the best evaluators of their children’s needs, including health and special equipment needs. To participate in transitions, parents must be prepared for the transition process. A transition from one program to another requires adjustments for both parent and child. Therefore, a smooth transition begins with the transition of the parent. Examples of ways the delegates have participated in transitions and prepared their children for them included touring a new school or health facility with the child, introducing children to new people to acquaint them with new teachers or specialists, and learning a program’s daily routine and talking to children about it before immersing them in it. The groups all agreed that making these preparations for any transition is important to everyone’s well-being. The parents recommended that health providers, school administrators,

and service providers develop transition resource manuals concerning their programs and services for families.

Agreement was unanimous that parents must be good recordkeepers in order to make successful transitions; the parents must also ensure that records are transferred when a child makes a transition out of one health, education, or social service program or system and into another. These records, the delegates pointed out, include financial records for program eligibility, medical records for immunizations and tests taken, and school records for credits.

During transitions, as well as in other stages of working with the systems, the delegates said parents must demand respect and develop self-esteem for themselves and their children. To help ensure children's self-esteem during transitions, parents must make sure the children know their feelings about transition are important. Some parents have a special responsibility for developing the self-esteem of their children and making transitions smooth. Parents with children in

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special programs, for example, must make sure they don't fall prey to the stigma that others often create when children need more than usual services. The parents complained that practitioners do not value parents as human beings. They were critical of people administering health, education, and social service programs who sometimes act as though they own the children. Phrases such as "parents are professionals, too" and "label cans, not kids" were voiced throughout the conference.

The delegates agreed that parents need to be good role models, and becoming good models sometimes means finding good models for themselves first. It also means that parents need to watch out for other children in the community, and teach better parenting skills to parents who don't adequately fulfill the role of parent.

As the conference was ending, one delegate commented, "I thought I was a pretty good parent when I came here. But with all I've heard and learned here, I know I'll be a better parent in the future." The other delegates agreed with this sentiment and added that the

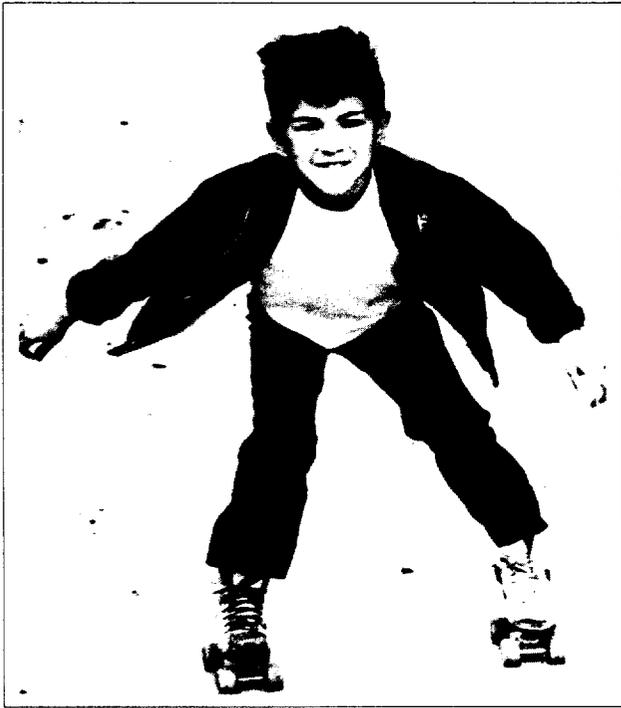
Conference has given them a new role: They have been charged with the responsibility of returning to their communities to meet with officials of programs that affect their children and to define the role of parents for the professionals involved.

### Barriers Families Face During Transitions

To open a dialog on barriers to successful transition, the delegates focused on one question: What makes it difficult for my child and me to move from one program to another?

One universal need for making transitions more successful was for parents, providers, and government officials to improve communications. The parents felt that better communication among agencies would decrease turf wars, prevent duplication of services, and promote the continuity of services. The delegates voiced concern that, too many times, they have found that professionals in office A don't know what programs are available through office B—even when A and B are under the same umbrella agency. The parents pointed out that one-stop shopping is just as important for smooth transitions as it is for entry into programs. They also called for development of one universal application form for a variety of public assistance programs, such as WIC, AFDC, and Food Stamps. They insisted that transitions would be smoother if files were tracked through a computer system that is accessible to staff in all State programs.

Parents said they need to receive the reports written about their children so that they can assume the role of recordkeeper. But if reports and other program materials are to be useful, they cannot contain technical jargon. Instead, they must be written in the language of the parents. That might mean having materials in foreign languages for parents who do not speak English or having them developed as picture books for parents who are illiterate. One delegate told of a Spanish-speaking mother of a mentally retarded girl who attended public school. For 4 years, the mother did not know about the child's educational progress, problems, or needs because everything she received from the



school was written in English, and none of the school staff spoke Spanish.

Parents repeated that, during transitions (as in other phases), program materials and staff must be sensitive to all different types of cultures; they must be sensitive to social and financial status, too. The delegates complained that case workers tend to stereotype and pigeon-hole people, too often ignoring clients' backgrounds and histories. Successful transitions, the delegates said, depend on everyone involved trusting each other; inappropriate communications do not breed trust.

Another universally noted need was for parents to be involved consistently during transition. Parent boards that are proportionately representative of ethnic, racial, and cultural differences give all parents an important voice in program design and policymaking, which can help them prepare their child for transition. After transition occurs, parents still need to be involved. The parents repeatedly cited Head Start as a good example of a program that keeps parents involved; but after Head Start, parents need to make an extra effort to stay involved in their children's other educational opportunities.

The delegates said that support groups are needed even more during transitions, and they advocated that programs work with support groups to make transitions more positive. But even if support groups are not available, delegates said programs should provide counselors to help get parents involved and to prepare them for transitions into and out of programs.

Once again, the work groups cited a need to decrease the time parents spend on paperwork by developing less complex forms. In addition, delegates said agencies must be directed to reduce the time they take to decide an applicant's eligibility. Implementing these changes would help families make more timely transitions and provide more motivation for families to move from one program to another.

Delegates from small towns everywhere pointed out that families in rural America often have no resources in their hometowns to meet some children's health, education, or social service needs; travel distances to available providers can be long, and public transportation is seldom available.

If transitions are to be successful, programs need to be as flexible as program administrators expect the families to be. Flexibility should begin with program eligibility criteria and then continue to the program structure and facilities. Many delegates remarked that family and individual needs still exist when income levels change, but eligibility criteria are often too rigid to accommodate the transition. Too often, the parents noted, agencies overlook the need for their offices to be open when parents can gain access to them, after traditional business hours or on weekends, for example. A story from one delegate, the mother of a child with physical disabilities, documents the need for flexible facilities. The child's classroom contains a restroom. However the delegate's son, who uses a wheelchair, and his attendant were not allowed to use these facilities because he requires more time than the other children. They had to go across the school gym to a communal restroom because the teachers didn't want the other children waiting in line for the boy. Some flexibility in the program would have made him feel more welcome and comfortable, and it would have made his transition to the classroom much more positive.

Labor laws need to be enacted to make employers more considerate of the needs of people with children, particularly poor working parents. One parent delegate surprised even her understanding colleagues when she told that her employer, a hospital, would not give her time off to come to the Surgeon General's Conference; she had to deduct the Conference from sick and vacation leave, which she also uses when her child has a medical appointment or a day off from school.

Parents reported that they and their children are constantly facing new transitions. They suggested that some of these transitions and their associated problems could be eliminated, if all levels of government would stop the frustrating practice of abolishing programs that families depend on without notice. Unstable funding from all levels of government is another frustrating barrier parents hurdle during transitions in health, education, and social service programs. The parents felt strongly that funding should not be based on grants or time limits.

## TRANSITIONS

### **Solutions, Resources, and Partnerships for Improving Transitions**

As in the other stages, improved communication during transitions was one of the most often cited needs, and parents repeated their suggestions of using 800 numbers for information clearinghouses and hotlines, especially for State program information, and creating local phone directories for resources or computer databases that would be updated yearly with current information on various programs. Some delegates noted that hotlines need to have bilingual operators who are representative of the calling population. One delegate commented, "Where's 1-800-MEDICAID? There's no trouble finding 1-800-SEX."

To address the need for culturally relevant programs and culturally sensitive staff people, the delegates suggested that professionals, particularly the first points of contact in a program or service, be given sensitivity training so they know how to avoid offending

people from various ethnic backgrounds, social classes, and financial means.

Parents said they could use guidance through the health, education, and social service systems. One such guide they proposed was using system veterans as mentors for new parents; these veterans could become personal mentors or could develop resource manuals that parents new to programs would receive for assistance and advice. They could also encourage new parents to seek out community-based groups, particularly support groups.

Doctors and hospitals could provide guidance to parents through expanded prenatal and parenting training. They could also distribute information and do outreach for State and community programs through packets that would be given to every parent of a newborn. Service providers could assign a full-time staff person to help people with transitions into and out of the program or service.

A number of regions discussed total community ownership of programs as another solution to promoting parental involvement. In other words, programs have to be familiar to everyone in the community, not just parents. It is also important to involve parents in evaluation teams for clinics, schools, and social service agencies.

The delegates found no shortage of solutions, either, for how to decrease paperwork and modernize programs. As was previously discussed, every work group advocated one-stop shopping, sensible hours that fit parent schedules, and the use of a single form for several assistance programs. Likewise, many parents proposed that one case worker be assigned to work with a family for all public assistance programs, rather than one worker for each program. This practice would allow families and case workers to develop a more trusting relationship and would reduce duplication of questioning and processing.

The delegates also offered more solutions to the problem of rigid eligibility standards. The delegates suggested that assistance programs base their decisions on take-home pay, not gross income. One mother said, "If I brought home my gross pay, I wouldn't need the services."

The delegates also suggested that the Government develop hardship deductions that would be used in calculating eligibility for services and programs. Another call was for a safety net for families who don't always fit within the parameters of assistance programs but are needful of help, even for a short time. An example of such a situation came from a southern delegate who told that she was living in the north when her doctor said her child was dying and needed to live in a warm climate. She and the child moved to Florida, but the father, who couldn't find a comparable job in Florida, stayed in Michigan. The woman applied for some assistance but was told she wouldn't be eligible unless she first filed abandonment charges against her husband.

All work groups discussed legislative solutions and regulatory relief to some of the barriers to successful transitions. One remedy, the delegates agreed, is that parents have to support and elect family advocates at all governmental levels. Another recommendation is for the Government to simplify application and eligibility requirements. A third solution involves getting parental leave bills passed; they have been proposed but now they must be enacted so that parents, especially poor working parents, can have time away from their jobs without being penalized when a child needs to see a specialist or go to an interview for a new educational program.

A number of delegates expressed concern that laws supporting families have been enacted but are not being enforced, at least not everywhere. Delegates from New York, New Jersey, and Puerto Rico, for instance, made a laundry list of needs that delegates from the Virgin Islands said their territorial government is addressing through the provisions and mandates in the Education for All Handicapped Act (Public Law 99-457), which targets children aged 0 to 2 who are at risk.

The parents did not let themselves off the hook as far as developing solutions was concerned. The parent-directed solutions included acting assertively on the child's behalf, teaching children their rights so they can become their own advocates, training them to be cooperative (even when others are not), helping them understand it's not their fault when difficult teachers or

caregivers can't be circumvented, and confronting teachers who don't respect children or who belittle them, especially in front of other children.

### **Programs That Parents Grade A+**

When the delegates were asked to make a wish list of what a model program would be like, succinct descriptors were given quickly. In summary, the parents said programs must be child-centered and family friendly, be easily accessible, have broad eligibility standards, be antidiscriminatory and multilingual, be well promoted, provide individualized service, be staffed sufficiently, and have hours of service that are convenient to parents.

Parents also cited a number of programs that they felt were exemplary in their administration or service. Public Law 99-457, for children at risk aged 0 to 2 years, is a good example of a seamless and effective system. New parents need to be targeted for special attention. Public Law 99-457 should be expanded to benefit older children and children who do not have special needs, and should include family planning and prenatal and neonatal services. More vaccines could also be delivered through this program. Other generic programs, or those based in many States, included Head Start, school-based clinic programs, Home Instruction Program for Preschool Youngsters (HIPPY), workshops on the development of Individual Education Plans (IEPs), United Way services, Pathways to Understanding, and Family Resource Centers. Local or regional programs are listed in the descriptions of individual work groups, which follow.

The delegates offered these recommendations with the hope that many of them will be implemented. One parent concluded, "We've said all this before; is anyone listening?"

# Regional Issues

## REGION 1

CONNECTICUT

MAINE

MASSACHUSETTS

NEW HAMPSHIRE

RHODE ISLAND

VERMONT



Region 1 delegates stressed the importance of good prenatal care, family planning, neonatal screening, and early health intervention programs. To increase awareness of such programs, information on the programs should be available in public libraries. A catalog of available services, explaining eligibility criteria and benefits, would help parents as they enter the systems. The delegates recommended that application processes be streamlined, beginning with a single application form, if possible, for all services. Application forms should be adapted to linguistic and cultural differences. The blind, the hearing impaired, and those with low literacy levels need special attention. Social service and health care providers need to adjust or stagger their office hours for working parents. The parents' transportation needs also should be addressed.

### Region 1

## Recommendations at a Glance

#### Awareness and Entry

- ★ Make information on health, education, and social services available in public libraries
- ★ Streamline the procedures to apply for services
- ★ Adapt application forms to linguistic and cultural differences
- ★ Offer flexible hours for services
- ★ Address transportation needs

#### Participation

- ★ Encourage parent participation and advocacy
- ★ Inform parents of their rights; publicize program policies and parents' options
- ★ Make service providers accountable
- ★ Understand the needs of parents, particularly single parents

#### Transitions

- ★ Determine readiness for transition by abilities and developmental stages rather than by age
- ★ Maintain consistent philosophies among programs
- ★ Train parents in the curriculum being used and demonstrate ways to supplement it
- ★ Train providers to be sensitive to differences in ethnic, financial, and social status

To participate fully in the health, education, and social services systems, the delegates strongly advocated that parents vote in national and local elections, join or form networks in their communities, and take a more active role in their school systems. They viewed advocacy for their children as a routine part of parenting in their relationships with teachers, doctors, etc., and not just in the realm of legislative activities. They stressed that service institutions need to be more flexible philosophically so that they can be more "parent driven" and that parents should

participate with schools and service providers as respected partners. For instance, parents should be allowed to attend in-service training sessions for service providers, and they should serve on boards that direct the activities of programs. Parents should be informed of their rights as they participate in the systems; i.e., policies and options should be not only written but also publicized. Policies that result in children being taken from their parents should be scrutinized closely. Parents should not be afraid to express their needs. The delegates also complained that social service and health care systems are rigid, bureaucratic, and overspecialized, with the result that parents feel lost within these systems. The delegates were concerned that the service providers are not accountable for the quality of service they provide. Parents need support from the systems and from their employers (e.g., flexible hours) to participate. Providers and employers must recognize that parents, particularly single parents, can't "do it all"; they have physical and emotional limitations (such as lack of time and an abundance of stress).

Parents from the New England States were concerned that children are subjected to transitions too often simply because their age dictates they move into a new program. These delegates felt that instead of chronological age, abilities and developmental stages should be the factors that determine readiness to move on, up, or out. They noted that this concern is especially important for children with special needs. Another concern peculiar to this group was that changes in philosophy among programs impede successful transitions. As a solution, they suggested that schools host parent workshops that demonstrate the curriculum and tell parents how they can complement it at home. Region I delegates echoed the sentiments of most other groups concerning how programs and people must be sensitive to differences in ethnic, financial, and social status. But this group added a unique parental role to the equation: Mothers and fathers must make sure that caregivers and service providers understand and appreciate individual family values, as well.

Among the model programs in the New England States that the delegates cited are Elliot's Healthy Kids



in New Hampshire, which coordinates nutrition education in schools; the Upper Valley Support Group in New Hampshire and Vermont; Growing Up OK in Bristol, Vermont; Early Childhood Group in Middlebury, Vermont; Collaboration for Children in Massachusetts; Early Childhood Network in Aroostook, Maine; Developing Capable People Transition Task Force and Child Find, both in Rhode Island.

## REGION 2

NEW JERSEY

NEW YORK

PUERTO RICO

VIRGIN ISLANDS



Region 2 delegates said that parents entering health, education, and social service systems should network with more experienced parents and play active roles in parents' organizations. The delegates also advised that resource coordinators be assigned to families to help simplify the entry process and assist the parents as they

learn about and access the programs they need. Application and entry procedures are far too daunting; parents can feel lost trying to enter the system. One-stop shopping for services was strongly recommended. Office hours must be built around the needs of working parents. In addition, agencies need to expand their public service announcements and make a greater overall effort to keep parents informed about available resources. The delegates recommended a toll-free information hotline, along with support groups and other programs designed to make parents, especially teenage parents, more aware of their responsibilities.

The Region 2 delegates felt that the parents' role in networking does not end with active participation in the systems. Parents should enlist other families into programs. The delegates also agreed that parents should have a stronger role in developing agency procedures and policy. Parents need greater representation on agency advisory boards. Parents also should be involved in reforming health, education, and social service systems to benefit families. For instance, the delegates cited numerous problems with Medicaid, such as lack of physicians who accept Medicaid and long waiting lists for those who do. In addition to needed reforms in services, the delegates cited a need to change our society's attitude toward families receiving assistance from the systems. They are stigmatized in the public's perception as lazy and uncaring, and even the social service workers often behave rudely toward parents. This situation causes high frustration levels for families who participate in programs and prevents others from participating. The delegates felt that this behavior by service providers is a symptom of employee burnout, and recommended that employees be rotated

Indicating their commitment to finding solutions to the problems discussed, the Region 2 delegates held an impromptu meeting on their own time to outline a proposal for establishing a model health, education, and social service system. The proposal calls for a Federal initiative mandating a partnership across Federal agencies, the Office of Management and Budget, key Congressional committees, and families representing local areas. The initiative would establish a formal structure for implementing the following principles at all local levels:

- ★ A client- and family-centered program philosophy that emphasizes parent involvement in children's programs, and that is accountable to the individuals served.
- ★ A creative and flexible atmosphere within the systems brought about by regulatory relief from bureaucracy and "red tape."
- ★ The standardization of eligibility requirements across all service programs and simplification of the process for establishing a client's eligibility.
- ★ Easier access to services provided by centralized directories of services, one-stop shopping, and flexible hours.
- ★ An integrated approach to service delivery using unified case management and followup.
- ★ The rotation of service personnel and continuous training and cross-training to reduce burnout and promote sharing of information across programs within the systems.
- ★ Increased parental community involvement. Parents could make valuable contributions, especially for public relations, outreach to new families, and advertising of services. To promote parent involvement, use a community-based approach and allow for flexible work schedules. Seek collaboration with businesses, churches, and other community organizations.

to different positions within their agencies on a regular basis. This solution would also provide employees with a wider range of experience and information about how their agencies work—information that they can pass on to parents.

Delegates from Region 2 considered the parent's role in transitions as acting assertively or aggressively and emphasized that it must begin as soon as a child's needs are diagnosed. It is the parent's responsibility, they said, to demand access to and information about the prenatal and postpartum care their child with special needs might require. However, to encourage parents to act assertively, they agreed, the Nation must develop effective parent education. That education is linked to another need cited by Region 2 delegates. They wanted the Surgeon General to know that the country needs to establish an infrastructure to assist parents through their children's continuous transitions. Another important issue to this group was the lack of quality control in services. They remarked that unless quality control in health, education, and social service systems is consistent, transitions will never be better than mediocre.

Puerto Rico's Project ESPA (Escuela Para Padres Adultos, Project School for Adult Parents) was singled out as a successful parents' support group. The New York Foundling Hospital was also mentioned as a model program. In New Jersey, the State Health Department's Catastrophic Illness in Children Fund provides grants to families who would otherwise be financially devastated by catastrophic illness.

In addition, the Region 2 delegates recommended establishing a Federal initiative to institute a formal structure for implementing several principles in health, education, and social service systems. In implementing this initiative, the Region 2 delegates recommended the following approach: (1) linking it to America 2000 or similar program; (2) involving the private sector; (3) borrowing strategies that work from existing model programs and integrating them vertically and horizontally into community programs; (4) designating the Surgeon General to head the initiative and enlist the participation and cooperation of all relevant Federal agencies; and (5) recruiting parents who represent the diverse communities of the United States to be the liaison between government, community, and business representatives in the initiative. The delegates recommended recruiting and organizing these parents through a national clearinghouse and compensating them as experts for their work on the initiative.



**Region 2**  
**Recommendations at a Glance**

**Awareness and Entry**

- ★ Support parent networks
- ★ Assign resource coordinators to assist families
- ★ Simplify application and entry procedures
- ★ Implement one-stop shopping
- ★ Have flexible hours for services
- ★ Expand public service announcements that inform parents of programs
- ★ Establish a toll-free information hotline

**Participation**

- ★ Recruit parents to enlist other families
- ★ Provide for parent involvement on agency advisory boards
- ★ Seek parent input for needed reforms in the systems
- ★ Seek ways to change societal attitudes toward families who receive assistance
- ★ Rotate employees to avoid burnout

**Transitions**

- ★ Educate parents to act assertively on behalf of their children
- ★ Establish an infrastructure to assist families in transition
- ★ Establish consistent quality-control measures across systems

## REGION 3

DELAWARE

DISTRICT OF  
COLUMBIA

MARYLAND

PENNSYLVANIA

VIRGINIA

WEST VIRGINIA

Region 3 delegates underlined the importance of special programs for teenage parents to help them cope with their role as parents and to make them aware of available services. They also expressed that entry into programs would be facilitated by barrier-free health care centers and resource coordinators for special needs children. To inform parents about available services, lists of services could accompany birth certificates; private doctors should always have such lists on hand. The special needs of foster children demand greater attention; medical charts and equipment for foster children with special needs should follow the children in a timely manner. Family leave would allow parents time not only to address their own infants' special health needs, but also to help other parents and their children. While all regions discussed legislative solutions and

regulatory relief to some problems families face, Region 3 delegates were the only ones who discussed supporting the fetal alcohol bill as part of the solution to making healthy children ready to learn. This bill would prohibit restaurants, bars, and liquor stores from selling alcohol to pregnant women. Also, because support groups are so important, funding should be provided to sustain them and cover basic operating costs. Additional funding is required to prevent turf battles among agencies and within the communities they serve.

### Region 3

## Recommendations at a Glance

### Awareness and Entry

- ★ Establish special programs for teenage parents
- ★ Establish barrier-free health care centers and provide resource coordinators for special needs children
- ★ Distribute lists of services with birth certificates
- ★ Pass a family leave bill
- ★ Pass the fetal alcohol bill
- ★ Provide funding for support groups
- ★ Expand program funding to prevent turf battles among various programs

### Participation

- ★ Make programs community based
- ★ Hire recipients of services to help administer services
- ★ Allow parental involvement in policymaking
- ★ Reform programs to increase sensitivity, provide better training for service providers, make better use of resources, decrease bureaucracy, and disseminate information more effectively
- ★ Create tax credits for parents who keep children with special needs at home
- ★ Create tax benefits for employers who hire persons with special needs or the parents of children with special needs
- ★ Make funds available for affordable daycare

### Transitions

- ★ Invest in preventive services
- ★ Promote continuity of services among the systems
- ★ Resolve problems on a systematic basis rather than a case-by-case basis

To enhance participation in the systems, the Region 3 delegates stated that programs should be community based whenever possible, administered by people who live in the communities. The delegates also recommended that the recipients or part-time recipients of services be hired to administer the services as well, to help bridge the gap between bureaucracies and families. They viewed the role of parents participating in the systems as that of decisionmakers who help empower families receiving services, although they admitted that the systems do not allow for parental involvement in policymaking. They were most concerned about the lack of cultural sensitivity displayed by the systems, lack of training for service providers, and the negative stereotyping of recipients of services. They also complained about the systems' bureaucracy and the poor use of resources, resulting in the lack of services in some areas, and the lack of information about services. The delegates from the mid-Atlantic States advocated financial solutions to parents' needs. They suggested creating tax credits for parents who keep children with special needs at home (rather than institutionalizing them at Government expense), creating tax benefits for employers who hire individuals with special needs or their parents, and making funds available for affordable daycare.

The Region 3 delegates maintained that transitions would be facilitated if programs focused on prevention of problems before crises occur. Although preventive services may require a higher initial investment, these parents asserted, they would present significant cost savings to the Government in the long term.

They also commented that there is a lack of continuity of services as transitions are made within the systems. Delegates told how some children with special needs were given assistive devices to help them in school but that the equipment remained the school's property. In some cases, the equipment was not even allowed to leave the building when the child went home for the evening; even more often, a child was not allowed to take the devices to a new school—even one in the same system—as he or she matriculated. The delegates warned that these policies do not promote smooth transitions for parents or children. A father

from Pennsylvania was able to add some hope to this discussion when he told how his State had bypassed the problem with a solution that benefitted everyone. In his State, parents of a child with special needs can spend up to \$1,500 annually on assistive devices such as reading boards. The parents buy the device, but are reimbursed by the State. Their child can use the item until he or she outgrows it or leaves the State school system. Then the equipment is returned to the school, where it becomes available to another child.

This regional group also advocated that solutions must be systemic: programs and services cannot continue to respond to problems on a case-by-case basis. One parent said her child's school had rerouted a bus so it could transport a child with disabilities. But that change in the route meant that some children rode the bus 4 hours a day. The school responded to a particular case, not the underlying problem that it did not have enough buses accessible to children with disabilities. When another child with disabilities needed transportation, the problem had to be readdressed. The parents maintained that the school system should have broadened its solution the first time by buying another bus and hiring another driver, a solution they felt would be cost effective in the long run.

Model programs cited by the Region 3 delegates include Pennsylvania's Development Disability, which funds support groups, and the Communication Council, which involved parents as it rewrote the State-level standards for special education; the District of Columbia's Equipment Loan program, which funds equipment for special needs children, and the Parents and Friends of Children with Special Needs, a parent support group; Maryland's Special Mothers in Training, a 5-week training program for parents with disabilities, and New Visions, a program that uses parents as case managers; West Virginia's Public Health Screening, designed to meet the needs of parents who do not qualify for Medicaid but cannot afford health insurance; corporate Adopt-a-School programs; and Virginia's Department of Education/Division of Special Education Programs, which provides information on child development.

## REGION 4

ALABAMA

FLORIDA

GEORGIA

KENTUCKY

MISSISSIPPI

NORTH CAROLINA

SOUTH CAROLINA

TENNESSEE



Region 4 delegates advocated that all Federal programs share a universal, easy-to-read application form to help simplify the entry process for parents. A central community resource clearinghouse, or referral center, supplemented by a toll-free hotline, could also facilitate the process for entering parents. The eligibility criteria should be the same for all programs, but they should be more flexible. Presently, the systems encourage "staying poor" to meet these rigid criteria. They stressed that incentives are needed for families to move beyond assistance. The delegates also recommended that education in parenting skills begin in junior high school.

Overall, the systems would be more responsive to parents' needs as they participate in programs if the parents had greater involvement in policymaking and

especially in the training of providers, many of whom behave as though they have no sense of the worth and dignity of needy families. These families face language barriers, attitudinal barriers, physical barriers at health care centers, long distances to the centers, and inflexible office hours. Working parents need special consideration. As a rule, the parents have no choice but to adapt to the systems' requirements, whereas, as one parent said, "The money should follow the child, not the other way around." They expressed a need for professionals who know the community, its resources, and the issues

### Region 4

## Recommendations at a Glance

#### Awareness and Entry

- ★ Develop a universal application form and simplify the entry process
- ★ Establish community resource clearinghouses, supplemented by a toll-free hotline
- ★ Establish flexible eligibility criteria and incentives for families to move beyond assistance

#### Participation

- ★ Involve parents in policymaking and training of service providers
- ★ Remove barriers of language, attitudes, physical limitations, distances, and limited hours
- ★ Provide professionals who know the community, its resources, and the issues facing families
- ★ Provide job stability and affordable housing
- ★ Establish family leave policies
- ★ Provide better daycare and respite care services

#### Transitions

- ★ Involve parents in peer group visitation programs
- ★ Allow family time to reassure children during transitions