

*The Children's Behavioral Health Summit
May 11, 2004*

VOICES

Families as Partners in System Reform

SUMMIT REPORT

our greatest natural resource is the minds of our children. walt disney

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Introduction

This booklet serves to document the proceedings of the Rhode Island Children's Behavioral Health Summit, *Voices: Families as Partners in System Reform*, which took place on Tuesday, May 11, 2004, at the Crowne Plaza Hotel in Warwick, Rhode Island. Every effort has been made to capture the essence of the remarks of each main speaker and the tone and content of each of the working groups which were a part of this important event.

The Appendix contains supporting information distributed at the summit and the full list of recommendations that came from the workgroups.

Andrea V. Ferreira, MPH, CHES
AVF Consulting, Lincoln, Rhode Island

Overview

On May 11, 2004, the first ever Rhode Island Children's Behavioral Health Summit, *Voices: Families as Partners in System Reform*, took place at the Crowne Plaza Hotel in Warwick, Rhode Island. Over 150 participants – from federal and state lawmakers to youth, family members, volunteers, and social service providers – listened and learned together in plenary sessions, over lunch and in five intense workgroups around the Summit theme.

What emerged from the day, specifically from the five workgroups, was a call to action in the form of recommendations to DCYF and its partners. An important outcome of this event was also a renewed commitment from all sectors to further develop policies, practices, and services that are community based, family centered, and culturally competent.

Co-sponsors:

RI Department of Children Youth and Families, Division of Children's Behavioral Health and Education

Parent Support Network of Rhode Island

Office of the Governor

Rhode Island Department of Health

Rhode Island Department of Human Services

Rhode Island Department of Mental Health, Retardation and Hospitals

Rhode Island Department of Education

Rhode Island KIDS COUNT

Neighborhood Health Plan

Blue Cross Blue Shield

United Behavioral Health

*Participants were invited to
“listen to and develop action steps
to direct our work as a state...
to ensure that state policies and practices
and the services we implement and sustain
are crafted with, by, and for
the children and families who use them.”*

*Dr. Janet Anderson,
Assistant Director of the DCYF
Division of Children's
Behavioral Health and Education*

Summary of Recommendations to Ensure Family Voice in the Statewide Children’s Behavioral Health System

Eighteen recommendations emerged from the workgroups and fall into four principle categories, which are as follows:

1. Strengthen/expand existing child and family programs and services.
2. Strengthen and empower families by increasing their knowledge and skills.
3. Institutionalize meaningful family engagement in governance, financing, and quality-assurance activities at all policy levels, including developing and implementing formal mechanisms at the state level.
4. Remove barriers to family accessibility to decision-making.

The five workgroups identified their top recommendations which are outlined under:

1. Respite Care
2. Family Centered Neighborhood Based Services
3. Transition of Priority Populations at 18 – 21 Years Old
4. Family Involvement in Policy Decisions for Funding
5. Program Evaluation and Quality Assurance

A full description of each workgroup, including a list of panelists, the content of the discussion, and the workgroup’s top recommendations and suggestions, begins on page 14. In the interest of “banking” all the excellent ideas that emerged from each discussion, the Appendix contains the full lists of recommendations and suggestions for action steps related to incorporating and strengthening family voice in policy and practice.

Each Workgroup's Top Recommendations

(Refer to full description of each workgroup beginning on page 14).

RESPITE CARE: This workgroup discussed the current state of respite care for families of children with behavioral health issues and made recommendations to improve opportunities for family voice in the quantity and quality of respite care.

Recommendation #1: Include a line item in the state budget for respite care.

Recommendation #2: Bring families together in a forum to define the needs for respite care (e.g. CASSP/LCC/Support Groups). Use the forum to train families to advocate/be a voice; Bring legislators to the families in the family-friendly forum (e.g. in Support Groups).

Recommendation #3: Make meeting times family friendly.

Recommendation #4: Increase efforts by school districts to engage and inform parents; take concrete steps to work with parents. At the state level, this includes increasing engagement of families in the statewide special-education committee.

FAMILY CENTERED NEIGHBORHOOD BASED SERVICES: This workgroup focused on family voice in designing and implementing neighborhood-based services.

Recommendation #1: Build on the capacity and utility of effective systems. (LCC/CASSP)

Recommendation #2: Create ways for families to support each other (e.g. family mentors).

TRANSITIONS: This workgroup examined ways to include family voice to help youth and their families transition from the world of children's services to that of adult services.

Recommendation #1: Start planning for transition to adult services early – before the child reaches 18.

Recommendation #2: Develop support groups for parents of children in transition.

Recommendation #3: Talk about mental health and transition issues early.

Recommendation #4: Develop ways for youth to be involved in the community, including developing mentoring relationships for 14 year olds and creating opportunities for employment.



Cheryl Santos and Congressman Patrick Kennedy

FAMILY INVOLVEMENT IN POLICY DECISIONS FOR FUNDING: This workgroup reflected on both strengths and weaknesses of the current system and points of opportunity for family voices to be heard in decision making about funding.

Recommendation #1: Incorporate family members as leaders (and voting members) within the Children’s Cabinet. Parent representative from each of the state departments should serve on the Children’s Cabinet.

Recommendation #2: Conduct an organizational self-assessment to determine policies, structures, and practices that hinder family engagement (including cultural and linguistic competency) and change them. (Tawara Goode, National Center for Cultural Competence at Georgetown University initially suggested this, and the group concurred.)

Recommendation #3: Institutionalize policies and practices for incorporating family voice into policy and financing. Multiple departments have begun to value family involvement at this level. Beginning practices need to be institutionalized through departmental changes and/or legislation.

Recommendation #4: Parent involvement needs to be across the system – Have all state certification standards include a requirement for family governance – it is critical that provider agencies take this role as well as the state agencies themselves.

PROGRAM EVALUATION AND QUALITY ASSURANCE: This workgroup focused on the inclusion of family voice in program evaluation and quality assurance efforts by state and local agencies, organizations, and programs.

Recommendation #1: Develop a clear description of expected treatment outcomes against which families can measure progress and results.

Recommendation #2: Involve the family at intake.

Recommendation #3: Improve physical access to services: transportation, interpreters, respite care.

Recommendation #4: Create agency-initiated, family-involvement opportunities, such as Boards of Directors, Quality Improvement Committees, Agency Reviews (e.g. DCYF, JCAHO) and Outcome Evaluations.

Why We Gathered

Participants reacted enthusiastically to the first ever Rhode Island Children’s Behavioral Health Summit, *Voices: Families as Partners in System Reform*, held on May 11, 2004, at the Crowne Plaza Hotel in Warwick, Rhode Island. This invitational event was the result of a partnership of parents and youth with state and community agencies and organizations that represent and serve children and youth with special behavioral health needs. It was promoted as “an affirmation of the family voice in policy and practice” and marked a “momentous occasion” for DCYF and the Parent Support Network of Rhode Island.

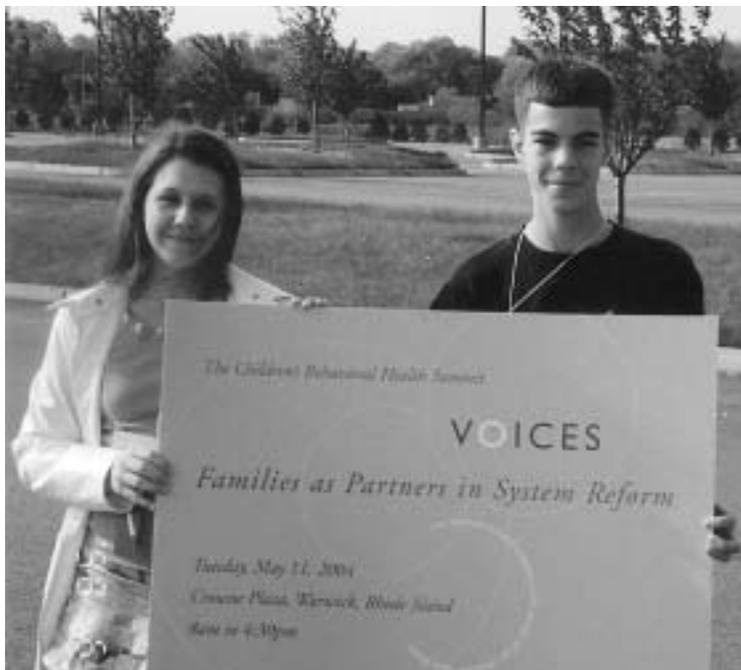
The Summit was structured to serve as the initial forum for a conversation among state policy and lawmakers, service providers, youth, families, volunteers, educators, insurers, administrators, researchers, and others focusing on children, youth, and families who need family-centered, neighborhood-based services. Its purpose as a working summit, according to Dr. Janet Anderson, Assistant Director of the DCYF Division of Children’s Behavioral Health and Education, was to take stock of the extent to which parents and families are true partners in system reform and to make recommendations to DCYF and its partners. She invited participants to join her to “listen to and develop action steps to direct our work as a state...to ensure that state policies and practices and the services we implement and sustain are crafted with, by, and for the children and families who use them.”

“Compelling”

“Commendable and ambitious effort.”

“Wonderful to see true family and youth engagement exemplified in a summit from planning to implementation.”

“Applause!! Applause!!”



*Karissa Santos and Peter Nunes,
members of “Youth Speaking Out.”*

Framing Our Point of Departure



*Governor
Donald L. Carcieri*

Following Dr. Anderson’s welcome, DCYF Director Jay Lindgren, Governor Donald Carcieri, and Congressman Patrick Kennedy offered remarks that served both to commend and to challenge the Summit participants to consider specific perspectives as they undertook the mission of the day. Both Congressman Kennedy and Director Lindgren acknowledged the serious and pressing need to provide effective and efficient children’s behavioral healthcare. Lindgren cited a serious weakness in the system in the fact that waiting lists for services are incredibly long.

Kennedy noted that in spite of the popularity of the topic of newborn brain development and its impact on early childhood services, children’s mental health is conspicuously absent from the agenda in Washington. Parity with healthcare coverage does not yet exist for coverage of mental health services. He also noted that many children have co-morbid conditions, such as substance abuse, which further complicate treatment delivery. Director Lindgren framed this serious state of affairs in terms of the Chinese word for “crisis,” a two-character word presenting the concepts of both danger and opportunity. The danger, he noted, is that children and their families are not getting what they need. However, the opportunities, he emphasized, do exist and need to be leveraged. The providers in the state are

*“We have this thought in
America about being self-reliant.
But if we really think about it,
there are always
people around us that helped us out.
This is especially critical for
our young people.”*

Governor Donald L. Carcieri



*Jay G. Lindgren, Jr.,
Director, DCYF*

“competent, gifted, and hard working.” He noted that what is needed is “a design and a system that makes those people do the best work possible.” He commented on several excellent examples around the state of what “bottom-up” and “top-down” efforts can yield on behalf of families, and the Governor is demonstrably supportive of this work.

Governor Carcieri further set the tone for the day’s events by reminding participants that the best way a business can learn what to do next is to ask the consumers of its product. He reflected on the fact that large institutions often get bogged down looking inward at their processes and can lose sight of why they do what they do. Yet one of the most effective business strategies, he noted, was that of the Japanese. They spend a seemingly inordinate amount of time defining a problem. Similarly, he encouraged participants to thoroughly analyze the situation and develop a consensus about the problem definition. This inherently leads to the best solutions.

危机

Crisis =

Danger + *Opportunity*

Youth Voice: Setting the Stage

(Facilitated by Bill Eyman)

The line of eight youth stood with their backs to the audience. One by one they turned around and declared the line “One of us...” and described an experience or condition of someone from among them.

Each of these young people came in turn to the microphone to open their hearts and share their experiences about what it has been like to live with mental health issues. Before a gathering of strangers, they laid out their struggles, their fears, and both their darkest moments and their redeeming ones.

Their courage and candor laid the foundation for this day of reflection, analysis, passion, and brainstorming.

What these youth shared with their audience helped to ground the participants in the day’s deliberations about families as true partners in the work of reforming Rhode Island’s system of children’s behavioral healthcare. Each of their stories were reminders that the issue is not merely about how clients and families are plugged into services, but about real children, youth, and their families and how a system of care must be shaped to best meet their particular needs. The Question and Answer period provided an opportunity for these youth to offer some practical advice. It clearly demonstrated how families at the table bring a wisdom and perspective that open ways to meet the real needs of children and youth.



“One of us ...

...has attempted suicide...

...has bipolar disorder...

...has been raped...

...has abused substances...”

“Youth presentation was extremely moving...great way to start.”

“Putting the youth first and foremost was great.”

–Summit Participants

Among their suggestions were:

- » Mentoring of younger youth by older youth;
- » Educating teachers, administrators, and juvenile-justice personnel to be alert, compassionate, and caring about the youth they serve; and
- » Educating other youth about mental health issues.

*“The real me is a bright person
and real leader and friend.”*

Alicia

*“I am grateful for the friends and family
members who love me as who I am.”*

Tonya

*“Just because I am up here showing no
fear, doesn’t mean I don’t have butterflies.”*

Jim

*“I learned my disability would not
keep me from succeeding.”*

Anthony



Keynote Address:

“How do we partner to ensure the family voice in the development, implementation, and evaluation of the children’s behavioral health system?”



(Dr. Joyce Burrell, Senior Juvenile Justice Specialist, American Institutes for Research)

Dr. Joyce Burrell has been there – there on the home front and in the trenches. She has been frustrated, as persons whom she loved were unable to access much-needed help or were caught between two systems. In her 20 years’ experience in juvenile justice, Dr. Burrell has worked to bring together the arenas of mental health and juvenile justice in the mix of service and care for youth (see her biographical sketch in the Appendix). She presented her own story, as the daughter of “a mother who suffered silently with major depression for many years and the godmother of a young woman who committed suicide...because she could not access integrated treatment for her co-occurring mental health and substance abuse disorders.”

With a conviction and passion that comes from both knowledge and experience, Dr. Burrell helped attendees understand how an effective system of care is the *only* appropriate response to meet the multiple needs of children and families with mental health issues and juvenile justice involvement. Public systems have been failing to meet the needs of these children and families including, to a great degree,

children of color. Interagency coordination has been the exception rather than standard practice, resulting in many, many children falling through the cracks. She described the nature of a system of care, the role of families in the system, ways to partner with families and what there is to gain from these partnerships.

According to the Surgeon General (2000), Dr. Burrell noted that fewer than one in four students with significant emotional and behavioral needs are receiving minimally adequate treatment, both in school and the community. This is compounded by child welfare and juvenile justice systems being overwhelmed by the prevalence of mental health issues among youth.

However, Dr. Burrell emphasized that an effective system of care can be developed if it operates on the basis of key principles, which include *families as partners, cultural competence, interagency collaboration, home*

A system of care is a comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of children and adolescents with severe emotional disturbances and their families.

Stroul and Friedman, 1986

“Is it too inconceivable to dream that by 2009 there would be systems of care for children with mental health needs in all our nation’s communities?”

Rosalynn Carter, 1996

and community-based services, individual strength-based care, and accountability. After a long history in this country of public agencies failing to serve children with mental health issues, and failing to understand or provide services that families need, the tides are turning. She affirmed that with regard to engaging families in serving and caring for troubled children and youth,

Rhode Island is well on the way and, in fact, serves as a model for many communities around the country in its recognition and integration of mental health services and juvenile justice. Youth involvement and engaging families as true partners are proving to be cornerstones to developing a system of care.

In her reflections on the progress made in Rhode Island along these fronts, Dr. Burrell was cautiously optimistic. She reminded Summit participants that many groups still are not being served, such as adolescents, as well as children with mentally ill or incarcerated parents. Few parents are well informed and even fewer are emboldened to challenge or even navigate the current system, she noted. There still remains a need for a workforce that is sufficient in size and properly trained and cross-trained, including in specialized law and in evidence-based practices. There is also a need for culturally competent service delivery, for parity in compensation for mental health, substance abuse treatment, and primary care and for sustained family involvement at all levels of policy making. She encouraged Rhode Island, in developing its system of care, to “tell its story,” to inform the public about the positive outcomes emerging from this work. Dr. Burrell noted that “systems of care” can evolve into something that all families are aware of and know how to access. As she aptly described, “We would then have caring systems.”



From left to right: Cathy Ciano, Executive Director, Parent Support Network; Marisa Brown, Senior Policy Associate for Family Engagement, Georgetown University; Tawara Goode, Director, National Center for Cultural Competence, Georgetown University; Janet Anderson, EdD, Assistant Director of Rhode Island DCYF for Children’s Behavioral Health and Education.

Overview – The System of Care Implementation Committee:



Tom Izzo, former RI State Senator, and

Patricia Martinez, Director of Community Relations, Office of the Governor

For the past two years, the System of Care Task Force has worked to establish a vision and process of creating a system of care for our state's vulnerable populations that is responsible, effective, and affordable. In January of 2003, the report of their work was published (*see http://dcyf.state.ri/tsk_force.pdf*). Patricia Martinez and Tom Izzo provided an overview of the work of the Task Force with a view to bringing a message of optimism. The Department of Children Youth and Families, Mr. Izzo noted, is better poised today to implement the changes that were recommended in that critical report. He credited key community partners such as Neighborhood Health Plan of Rhode Island and Chief Justice Jeremiah of the Family Court, as well as community advocates and families, as playing an essential role in changing the tide and impacting the way DCYF does business. He also spoke of rich opportunities and a dynamic process that is underway, while recognizing significant challenges. Among these is the real challenge of our juvenile justice system that still reflects a “bricks and mortar” perspective rather than a system of care for the state's most troubled youth.

Developing a system of care has become a main focus of the Children's Cabinet. According to Ms. Martinez, a more effective relationship between the Governor's Office and DCYF is developing. Through weekly meetings with DCYF at various levels, along with community partners, the work on re-creating Rhode Island's system of care is moving forward. Key to its success is changing the culture of the system into one that is based on best practices and is family-centered and community-based.

The participation of family members was well integrated throughout the Summit and is essential in our efforts for statewide system reform.



Lunch Speaker: “How do policy and practice incorporate cultural and linguistic competency?”



Tawara Goode, Director, National Center for Cultural Competence, Georgetown University

Ms. Tawara Goode brought her perspective on cultural and linguistic competence to the Summit to help participants utilize a theoretical and practical framework in their considerations of family involvement in systems of care. In her nearly three decades of experience, she has been deeply involved in child and human development. She has been actively involved in the development and implementation of programs and initiatives in the area of cultural and linguistic competence as well as programs for individuals and families at risk for and with behavioral and developmental disabilities (see her biographical sketch in the Appendix).

Over lunch, Ms. Goode guided the audience through definitions and concepts of culture, competence, cultural competence, and linguistic competence, and outlined how these are expressed at both the organizational and system levels. These fundamental definitions served as the basis for examining more complex issues related to cultural competence within the context of organizational change. To change an organization to make it more “competent” requires managing the change at a level that results in real change, not in frustration, false starts, anxiety, or confusion. This means more than just conducting a “cultural-competence training” session.

Ms. Goode outlined types of policy strategies and types of authority needed to facilitate systems reform. This includes things such as formal agreements, including contracts and interagency agreements, as well as program standards, licensing requirements, legislation, and executive orders. In the end, Ms. Goode pointed out that, for organizations serving children and youth with social, emotional, and behavioral disorders and their families, the implications for cultural and linguistic competence at the policy-making level will have a fundamental impact on the way the organizations do business. Cultural and linguistic competence requires that an organization, agency, or system examines what it does, who its staff should be, where its money goes, who its partners are, and to whom it entrusts delivery of its services and support.

Working Groups

After lunch, participants selected *one* of five Working Sessions:

1. Respite
2. Family-Centered, Neighborhood-Based Practice
3. Transition of Priority Populations at 18-21 years old
4. Policy Decisions for Funding
5. Program Evaluation and Quality Assurance

*“It gives me tremendous hope
that we can make a difference.”*

*Evaluation of Event
by Summit Participant*

The charge to each workgroup was delivered by Cathy Ciano, Executive Director, Parent Support Network of RI. Each workgroup was responsible for developing two to three recommendations about how to institutionalize family involvement, particularly family voice, in Rhode Island’s system of care.

Each workgroup was structured similarly and was facilitated by a staff member from Rhode Island KIDS COUNT. First, a panel in each session, comprising five to six individuals with expertise and/or experience with the issue, shared their perspective as a jump-start to the list of recommendations.

The rest of the workgroup session further engaged participants in thinking about and creating two important lists to respond to two basic questions:

1. What is the current level of family involvement in the issue?
2. What can be done to incorporate or improve the family voice in policy or practice regarding the issue?

The workgroups were strictly charged to come up with specific action steps related to this second question. Once a list of recommendations was constructed, group members prioritized recommendations by attaching stickers to their top two to four.

The essence of each workgroup discussion is presented in the following pages. For the most part, a summary of the panelists’ comments is presented first, followed by a summary or list of key issues raised by participants. Each section ends with the top recommendations that emerged from the group. The complete list of recommendations from each workgroup is found in the Appendix. In several cases, some of the recommendations received only one or two votes and are actually specific strategies directly related to the final recommendations put forth by the group (e.g. provide food at meetings, create phone trees).

Breakout Session #1 – Respite Care (Facilitator: Veronica Kot)

This Workgroup discussed the current state of respite care for families of children with behavioral health needs and made recommendations to improve opportunities for family voice in the quantity and quality of respite care.

Panel members presented their perspectives about respite care. Regarding existing family involvement, several panelists noted specific programs where families are provided some opportunity for expressing their voice regarding respite care: CASSP with its focus on the whole family; fostercare parent programs; the Parent Support Network, specifically its peer mentoring program and Youth, Parent, DCYF Partnership; RIte Care; and the statewide special education committee’s subcommittee focusing on family engagement. Other than these specifically named venues, they observed that

opportunities for voicing family needs for respite care are few and far between. Most successes appear to be at the community level; and at best, this is spotty. Thus, families often find themselves facing complex issues involving their employment, limited access to care, and a profound sense of feeling overwhelmed with few options for having their needs addressed. While families themselves define the type of respite they need, and a one-size-fits-all solution is not an option, the lack of any coordinated, effective way for families to receive respite care is particularly noticeable at the state level.

Additional Issues: In the discussion, parents noted that dealing with schools is often a source of great stress. In an effort to keep to the charge of their workgroup, parents acknowledged this was not the exact

focus of a respite-based discussion but emphasized that dealing with schools is a very difficult process for them. Respite for parents is critical because they spend so much time and energy working with schools. This is time and energy that jeopardizes their jobs and is enormously stressful, even for the most competent parent advocates. The basic sentiment is that schools need to engage parents in positive ways.



*Merceides Goetzinger,
member of Youth Speaking Out*

Panel Members

Senator Elizabeth Roberts (RI Legislature)

Joelle Reed (Parent)

*Deborah Florio
(Department of Human Services)*

Laura Jones (Parent)

Pete (Youth)

Christine (Youth)

RECOMMENDATIONS (Full list of recommendations are included in the Appendix.) Recommendations are listed in order of priority:

Recommendation #1: Include a line item in the state budget for respite care.

Recommendation #2: Bring families together in a forum to define the needs for respite care (e.g. CASSP/LCC/Support Groups). Use the forum to train families to advocate/be a voice; bring legislators to the families in a family-friendly forum (e.g. in Support Groups).

Recommendation #3: Make meeting times family friendly.

Recommendation #4: Increase efforts by school districts to engage and inform parents; take concrete steps to work with parents. At the state level, this includes increasing engagement of families in the statewide special education committee.



Members of Youth Speaking Out

Breakout Session #2 – Family Centered Neighborhood Based Services (Facilitator: Kat Pannhorst)

This workgroup focused on family voice in designing and implementing neighborhood-based services.

Several themes emerged in the panel discussion of family voice in designing and implementing neighborhood-based services. Panelists, who represented specific service providers, presented their perspectives and experiences of engaging families in service-delivery decisions. Not surprising, much of the family engagement underway at the community level takes place on an agency-by-agency basis. Yet panelists identified several important, common factors in their work that create opportunities for family voice: the agency’s cultural competence, including having bilingual/bicultural staff who live in the community they serve; having a whole family focus on service delivery; attempting to coordinate services and programs within their organization and among the various providers to meet families’ multiple needs; and holding formal and informal meetings with families in various community settings (e.g. at schools, community fairs, etc.). They also pointed out

Panel Members

Glen Johnson (John Hope Settlement House)

James (Youth)

Jennifer Irish (DCYF, Project Hope)

Benjamin Lessing (Family Resources)

Ed Cancel (Progreso Latino)

several client factors and organizational factors that greatly impact opportunities for family voice: length of time service is needed by/provided to a family, multiple family needs, program effectiveness, policies that enable/restrict DCYF staff, and lengthy waiting lists.

The participants in this workgroup were eager to discuss this issue and provided several additional examples of effective ways to engage families in neighborhood-based services. CASSP, Local Coordinating Councils (LCCs), and the Parent Support Network were most often cited. Participants also pointed out numerous particular “weak spots” in the current service-delivery system. If addressed, they noted that these could serve as opportunities for family voice at the neighborhood level. An analysis shows that their comments fell into three categories: *state-level systems*, *local-agency policies*, and *family empowerment*.

RECOMMENDATIONS (Full list of recommendations are included in the Appendix.)

Recommendations are listed in order of priority:

Recommendation #1: Enhance and expand effective venues (LCC/CASSP).

Recommendation #2: Create ways for families to support each other (e.g. family mentors).

This group also identified several specific strategies which are grouped here by theme.

STATE-LEVEL SYSTEMS

- » Link work of DHS, RIDE, and DCYF.
- » Increase sharing of knowledge, resources, and effective programs.
- » Expand effective venues (e.g. LCCs, CASSP).
- » Strengthen accountability at both the local agency and state agency levels.
- » Scale up efforts (from local focus to Children’s Cabinet level).
- » Address needs of undocumented residents.

LOCAL AGENCY/ORGANIZATION POLICIES

- » Engage the community to support families.
- » Create venues for parent-to-parent mentorships.
- » Link youth returning to the community with local services.
- » Ensure that parent representation on Boards is not token; treat them as professionals.
- » Clearly define the community’s role in decision making, including sharing power.
- » Integrate the school system as well as private/non-profits in a continuum of care.

FAMILY EMPOWERMENT

- » Educate parents/families as to their roles, rights, and responsibilities in the system.
- » Educate and communicate with families/youth to reduce fears about using services.

Breakout Session #3 – Transition of Priority Populations at 18-21 years old (Facilitator: Raymonde Charles)

This Workgroup examined ways to include family voice to help youth and their families transition from the world of children’s services to that of adult services.

The topic of helping youth and their families transition from the world of children’s services to that of adult services elicited some passionate responses as well as very concrete suggestions from this workgroup. Panelists presented several examples of youth who made the transition into the world of adult services and those who fell through the cracks. They also pointed out that the important link between schools and community-based programs is often not well tended. The Office of Rehabilitation Services (ORS) was cited as an example of a program that has proven helpful to many young adults and their families. Additionally, the Division of Behavioral Health and Education at DCYF was cited as helpful, and the Rhode Island Department of Education has developed a guide for families in transition. Workgroup participants added to these examples, presented anecdotes of their own, and identified several significant factors associated with this transitional period in a young person’s life and the impact on family involvement.

Members of Youth Speaking Out gave a powerful presentation detailing their life experiences growing up with mental health challenges.

Panel Members

Janice Pangman (Parent)

Robert (Youth, Project Hope)

Charles (Youth, Project Hope)

Charissa (Youth, Project Hope)

Thomas Martin (Department of Mental Health, Retardation and Hospitals)

David Sienko (Department of Education)

Regina Connor

(Office of Rehabilitation Services)



Specifically, they noted:

- » The level of family involvement during this transition period depends upon the disability. On the one hand, the individual's competence to make decisions may be an issue. The level of impairment can also impact a person's willingness to seek help. On the other hand, mental health laws protect client confidentiality, which often precludes family involvement.
- » At 18 years of age, young people are being encouraged to become more independent. Family involvement can be both helpful and intrusive in this process. Additionally, a young person may choose to "close the door" on family at this point in time, and services can begin to fall away.
- » The critical role of schools cannot be overstated, and the special education teacher must be a key player in a transition plan. Nonetheless, for some families, the culture of schools can make schools unwelcoming places. At the same time, it is not realistic to rely on the special education teacher in a school to be the principle player in a transition plan, especially when she/he often has too many roles and little decision-making power.
- » Clinicians often ignore family participation in the transition process. Treatment should actually focus on maintaining important relationships.
- » Family resources and skills are major determinants of sustained family involvement during this time.

RECOMMENDATIONS (Full list of recommendations are included in the Appendix.)

Recommendations are listed in order of priority:

Recommendation #1: Start planning for transition to adult services early – before the child reaches 18.

Recommendation #2: Develop support groups for parents of children in transition.

Recommendation #3: Talk about mental health and transition issues early.

Recommendation #4: Develop ways for youth to be involved in the community, including developing mentoring relationships for 14-year-olds, and creating opportunities for employment.

Breakout Session #4 – Family Involvement in Policy Decisions for Funding (Facilitator: Catherine B. Walsh)

This workgroup reflected on both strengths and weaknesses of the current system and points of opportunity for family voices to be heard in decision making about funding.

The workgroup began with remarks by the five panelists about the current level of parent involvement in policy decisions for funding. As policymakers, their perspectives reflected both strengths and weaknesses of the current system and points of opportunity for family voices to be heard in decision making about funding. Several of the panelists identified ways that their office or organization enables family involvement/ family voice.

These include:

- » Focus groups, consumer surveys, provider surveys
- » In-person family surveys at community events
- » Agency involvement in a wide variety of state level initiatives (e.g. United Way Summit)
- » Consumer advisory panels (e.g. NHPRI, RIte Care)
- » Youth, Parent, DCYF Partnership
- » Interagency Coordinating Council for Early Intervention
- » Special healthcare Needs Roundtable
- » Children’s Policy Coalition
- » RIDE Special Education Advisory Group
- » Progressive involvement of families from consumer feedback, to input on program/service design, to quality-assurance functions

Panelists also collectively described issues related to family engagement in funding decisions. It was noted that the intersection between policy and planning at the state level is confusing and messy. While there may be the resources to address children’s behavioral health issues, currently these dollars are not effectively used. When parents/families are not at the table in meaningful, sustained ways, state agencies tend to make decisions about what families need. This leads to services that can be irrelevant or more complex than they need to be. Panelists also noted that “early” is a key concept. Children’s behavioral health problems must be

Panel Members

*Cathy Ciano (Adult Family Member,
Executive Director, Parent Support Network)*

*John Young (Associate Director,
Department of Human Services)*

*Janet Anderson (Assistant Director,
Dept. of Children, Youth and Families)*

*Kenneth Pariseau (Director, Special Programs,
Neighborhood Health Plan of Rhode Island)*

*Rep. Thomas Slater
(Rhode Island General Assembly)*

addressed early. Families must be deeply involved in their child's behavioral healthcare early on. Intervention with children involved with Family Court must include continuous parent involvement from the beginning.

Providers have learned to bring their voice to the legislative table with their point of view based on the services they deliver. Panelists expressed that parents/families can also learn to bring their point of view to legislators based on what they need, what they want, and how they want it. Panelists stressed that legislators need to hear directly from parents/families affected by children's behavioral health issues, including how they access and use services. They also noted that legislators need to build their understanding of the link among healthcare, childcare, children's behavioral health issues, and the juvenile justice system. Decisions in any one of these areas impact the others. For example, as the state is moving toward making the Training School more community based, it is critical that families be at the table for this strategy to be effective.

Panelists also recommended that support for meaningful, sustained parent/family input be included in state agency budgets. They also suggested that speaking in jargon with families be eliminated so that communication can be effective.

Once the panelists presented their perspectives, each participant spent time developing two recommendations for improving family participation in policy decisions about funding. Each participant read their two recommendations, and they were discussed and recorded on a master list. As with the other workgroups, participants reviewed the entire set of recommendations and voted with stickers for the most important ones.

RECOMMENDATIONS (Full list of recommendations are included in the Appendix.)

Recommendations are listed in order of priority:

Recommendation #1: Incorporate family members as leaders (and voting members) within the Children's Cabinet. A parent representative from each of the state departments should serve on the Children's Cabinet.

Recommendation #2: Conduct an organizational self-assessment to determine policies, structures, and practices that hinder family engagement (including cultural and linguistic competency) and change them. (Tawara Goode, National Center for Cultural Competence at Georgetown University initially suggested this, and the group concurred.)

Recommendation #3: Institutionalize policies and practices for incorporating family voice into policy and financing. Multiple departments have begun to value family involvement at this level. Beginning practices need to be institutionalized through departmental changes and/or legislation.

Recommendation #4: Parent involvement needs to be across the system – Have all state certification standards include a requirement for family governance – it is critical that provider agencies take this role as well as the state agencies themselves.

Breakout Session #5 – Program Evaluation and Quality Assurance (Facilitator: Theresa Hancock)

This workgroup focused on the inclusion of family voice in program evaluation and quality-assurance efforts by state and local agencies, organizations, and programs.

In keeping with the format of the breakout sessions, panelists focused their remarks on the inclusion of family voice in program evaluation and quality assurance efforts by state and local agencies, organizations, and programs. They discussed shifts in philosophy as well as changes in the ways families can be informed and how they, in turn, can inform agencies and providers.

Key points included:

- » Treatment philosophy needs to be shifted away from “fixing the client” to a strengths-based approach.
- » Families need to be involved at all important transition points in treatment, including intake and discharge.
- » Families should be involved at many levels, including treatment, policy development, and evaluation.
- » Families need more information about the diagnostic process, and they need to receive it from their peers.
- » Dissatisfied customers often provide the most valuable feedback.
- » The system is attempting to shift from high-end residential placements to community-based placements.
- » Family engagement is a challenge when services are provided in different settings and at different intensity levels.
- » Adolescent clients should be viewed as part of the family system and should be surveyed on satisfaction.
- » Families need help feeling comfortable in unfamiliar settings and with unfamiliar staff.

Next, the participants spent time developing their suggestions for improving family participation in evaluation and quality assurance. Each participant read suggestions aloud, and they were discussed and recorded on the master list. Participants reviewed the entire set of recommendations and chose four that they felt were most important.

Panel Members

John Susa (Adult Family member, Sherlock Center for Individuals and Families)

Ashli (Youth Family member)

Christine Brown (Bradley Hospital)

Elizabeth Ison (Placement Solutions)

Joyce Edmonson (Family Services)

RECOMMENDATIONS (Full list of recommendations are included in the Appendix.)

Recommendations are listed in order of priority:

Recommendation #1: Develop a clear description of expected treatment outcomes against which families can measure progress and results.

Recommendation #2: Involve the family at intake.

Recommendation #3: Improve physical access to services (i.e. transportation, interpreters, and respite care).

Recommendation #4: Create agency-driven, family-involvement opportunities, such as Board of Directors, Quality Improvement Committees, Agency Reviews (e.g. DCYF, Joint Commission on the Accreditation of Healthcare Organizations [JCAHO]) and Outcome Evaluations.

*“Now I know my voice
will be heard, and I’ll advocate until
I’m no longer breathing.”*

Summit Participant



*Colleen Hedden, Educational Services Coordinator, DCYF
Sophery Huy, Administrative Assistant, Parent Support Network.*

Closing Family Panel Presentation: Further Grounding in Reality.

(Facilitated by Bill Eyman)

Wrapping up the day was a session designed to elicit an honest conversation among adults and youth who are family members of a child or youth with a mental health issue. A group of eight invited guests formed a circle in the front of the room, and Summit participants observed in fish-bowl fashion. Aware that conversations about the day-to-day challenges of being in such a family take place during conferences, IEP meetings, and among family members, Mr. Eyman set the stage by inviting those in the group to answer the question, “What has been the impact on you personally of having a family member with mental health issues?”

In the course of a half hour, family members described some of the feelings and issues with which they have to contend.

These include:

- » Siblings feeling neglected, isolated, ashamed of the ill sibling, or in fear of the unpredictable behavior and moods. Some are puzzled by inequities in rewards and punishments.
- » Parents experience a range of feelings as well, from utter frustration and exasperation (“like hitting a wall at 100 mph”). Also mentioned was feeling burnt out as well as neglected by a system that offers very little to youth over 18. Others feel a quiet desperation as the school overlooks their child with depression because he/she is a good student.
- » Parents also are bothered when professionals make judgments about their parenting. A parent may be late 15 minutes for a meeting, because she has “just spent 25 minutes struggling with her son to get him into the car.”



Lynn Brailsford and Adrian Soto members of Youth Speaking Out.

Yet these family members also spoke of hope and strength and power that has come from wrestling with the system, making a difference for their child, improving themselves, and getting support from other parents. One parent described herself as being “nearly a professional” because of the number of years she has been dealing with professionals. Another feels that she is respected in her district and that the system has been responsive to her family and cultural needs.

“Dwell in possibilities.”
Emily Dickinson

As the group reflected aloud on their experiences, several referred to changes they are seeing in the system. There are more formal structures linking and coordinating care. There are also more venues for family input into decisions about care for their child. Youth described finding more responsive and caring adults in their educational or residential settings. These improvements have brought some hope and encouragement to these family members.

As the group discussion concluded and the circle opened to receive questions from the audience, Cathy Ciano (Parent Support Network of Rhode Island) invited them to share “the one thing you’ve learned in your life that would help others in similar situations.” What better way to wrap up the session than to hear their voices?

“There are other people around. There are days my brother and I have fights, but I will always be there for him and he for me.”

“I’ve learned to be an advocate for my family.”

“Don’t bottle up your emotions – let them out.”

“Talk about your situation. It reduces the stigma associated with mental illness”

“The Parent Support Network gave me hope so I can continue to go on and take care of my child.”

“Service providers are so important to each family that needs services. You will have an impact on what it is we do as parents and families. It’s really important that you all know that. Without you, we can’t do it. I commend each of you for being here. As families we need to push ahead. You help us do that.”

Next Steps

This document will serve as a critical tool to guide and inform:

- » ongoing policies,
- » decision making related to program development,
- » service delivery, and
- » quality assurance for the Rhode Island Children's Behavioral Health System.

The commitment from the RI DCYF, Division of Children's Behavioral Health and Education is to review the recommendations with its partners and the Youth, Parent, DCYF Partnership. If needed, the recommendations will be further defined. An implementation plan will be developed for the recommendations that are adopted for action. The voices of families bring a perspective that is absolutely essential to making the necessary changes for system reform and strengthening our understanding and ability to effectively respond to the needs of Rhode Island's children, youth, and families.

Closing Words

The first ever Rhode Island Children's Behavioral Health Summit was convened in a move that demonstrates the commitment of DCYF, Parent Support Network of Rhode Island, and other partners to meaningfully engage families in the important work to reform the system of care for children with behavioral health needs. According to the Summit organizers, the work of those involved in this event will be used to help operationalize the vision of an integrated, seamless, predictable, responsive, and effective system of care. The advice of experts, the wisdom of families and youth, and the recommendations of many providers, educators, and passionate volunteers came together in this event to outline specific action steps for DCYF and other child-serving systems and agencies in the next several months.

The work is cut out for us. As Assistant Director Dr. Janet Anderson stated in her closing remarks, *"This work is hard. We live it day after day... This is the continuation of a journey that many of you have been on for some time in this state... There's a lot to be learned and a huge distance to go."*

*"Do not be encumbered by history.
Go off and do something wonderful."*

Robert Noyce, Intel Cofounder

VOICES: *Families as Partners in System Reform*

8:00am REGISTRATION

Continental Breakfast

8:45 WELCOME

Jay G. Lindgren, Jr., Director, DCYF
Governor Donald L. Carcieri

9:15 YOUTH PRESENTATION

Youth Speaking Out, facilitated by Bill Eyman

10:15 BREAK

Coffee and...

10:30 KEYNOTE ADDRESS

Joyce Burrell, Senior Juvenile Justice Specialist, American Institutes for Research
“How do we partner to ensure the family voice in the development, implementation, and evaluation of the children’s behavioral health system?”

11:30 OVERVIEW

Chairpersons of the System of Care Implementation Committee:
Tom Izzo and Patricia Martinez, Director of Community Relations, Governor’s Office

12:00 LUNCH

Speaker: Tawara Goode,
Director, National Center for Cultural Competence, Georgetown University
“How does policy and practice incorporate cultural and linguistic competency?”

AFTERNOON CHALLENGE

Janet Anderson, Ed.D, Assistant Director of RI DCYF for Children’s Behavioral Health and Education;
Cathy Ciano, Executive Director, Parent Support Network of RI

1:45pm BREAKOUT SESSIONS

Sessions will address how we ensure that the voice of families is an integral part of the policy and practice for each of these topic areas:

1. Respite
 2. Family Centered Neighborhood Based Practice
 3. Transition of Priority Populations at 18-21 years old
 4. Policy Decisions for Funding
 5. Program Evaluation and Quality Assurance
-

3:15 BREAK

Light snack

3:30 FAMILY PRESENTATION

Family presentation, facilitated by Bill Eyman.

May 11, 2004

About the Presenters

JOYCE BURRELL

Joyce Burrell is a Senior Research Analyst at the American Institutes for Research working as the Senior Juvenile Justice Advisor at the Technical Assistance Partnership for the Comprehensive Community Mental Health Services to Children and Their Families' grantees in 62 sites around the country and the technical assistance partners funded by SAMHSA. Ms. Burrell has 20 years' experience working in juvenile justice, eleven of which were spent in leadership roles directly related to serving special-needs populations. As the Deputy Commissioner of the Philadelphia Department of Human Services, she was involved in the development and implementation of specialized programming for children with special needs who were also entering, at risk of entering, or in the juvenile justice system.

Joyce was a member of the Statewide Task Force on Barriers to Access to Mental Health Services for Dependent and Delinquent Children and Youth in Pennsylvania. She had oversight of the Court and Community Services Planning Group in Philadelphia, a committee comprised of community stakeholders. She was instrumental in acquiring statewide acceptance of the Massachusetts Youth Screening Instrument: Version 2 as the preliminary mental health screening instrument for 23 juvenile detention facilities. Joyce is credited with investing heavily in the evaluation of and expansion of the Philadelphia continuum of care to include evidence-based program services and such initiatives as Multi-Systemic Therapy, Functional Family Therapy, and the Bullying Program. These programs were added to existing traditional treatment programs and services in the city.

As president of the Council of Juvenile Correctional Administrators, Joyce had the opportunity to work closely with the 50 State Directors of Juvenile Corrections and Detention to look at the rapid growth in the numbers of mentally ill and behaviorally disordered/disturbed youth entering the juvenile justice system nationwide and the limited resources that were available to address the multiple needs these youth presented for juvenile corrections and detention. Joyce sits on the Advisory Board of the National Center for Mental Health in Juvenile Justice, and regularly represents practitioners at policy forums related to effective practices and interventions for youth with social, emotional, and behavioral needs.

About the Presenters

TAWARA D. GOODE

Tawara D. Goode, MA, is the Director of the National Center for Cultural Competence and Associate Director for Community Planning at the Georgetown University Center for Child and Human Development. She is an instructor in the Department of Pediatrics, Georgetown University Medical Center in Washington, DC. She has been on the faculty of the Georgetown University Center for Child and Human Development for the past 26 years and has served in many capacities. She has degrees in early childhood, special education and human development, and over 26 years of experience in the field.

As Associate Director for Community Planning of the Georgetown University Center for Child and Human Development, Ms. Goode is responsible for short-term and ongoing programs for individuals at risk for and with developmental and other disabilities and their families. Ms. Goode's duties include program development, administration, and teaching, within the university and community settings. In this capacity, Ms. Goode provided leadership in a multi-year effort to assist the District of Columbia government to close two institutions for individuals with developmental disabilities and establish residences and services in community settings. Ms. Goode assumes major programmatic and administrative responsibility for the University Center for Excellence in Developmental Disabilities Education, Research, and Service at the GUCCHD, funded by the Administration on Developmental Disabilities, U.S. Department of Health and Human Services.

Ms. Goode has been actively involved in the development and implementation of programs and initiatives in the area of cultural and linguistic competence at local, national, and international levels. These efforts address the needs of diverse audiences including healthcare, mental health, social services, early childhood and special education, community/advocacy organizations, professional societies/organizations, institutions of higher education, etc.

Ms. Goode serves on many boards, commissions, and advisory groups at the local, regional, and national levels. She has published numerous articles, monographs, and policy papers. Ms. Goode is a frequent presenter at National Conferences and Forums.

System of Care Values and Principles

CORE VALUES

1. The system of care should be child centered and family focused, with the needs of the child and family dictating the types and mix of services provided.
2. The system of care should be community based, with the locus of services, as well as management and decision-making responsibility, resting at the community level.
3. The system of care should be culturally competent, with agencies, programs, and services that are responsive to the cultural, racial, and ethnic differences of the populations they serve.

GUIDING PRINCIPLES

1. Children with emotional disturbances should have access to a comprehensive array of services that address their physical, emotional, social, and educational needs.
2. Children with emotional disturbances should receive individualized services in accordance with the unique needs and potentials of each child and be guided by an individualized service plan.
3. Children with emotional disturbances should receive services within the least restrictive, most normative environment that is clinically appropriate.
4. The families and surrogate families of children with emotional disturbances should be full participants in all aspects of the planning and delivery of services.
5. Children with emotional disturbances should receive services that are integrated, with linkages between child-serving agencies and programs and mechanisms for planning, developing, and coordinating services.
6. Children with emotional disturbances should be provided with case management or similar mechanisms to ensure that multiple services are delivered in a coordinated and therapeutic manner and that they can move through the system of services in accordance with their changing needs.
7. Early identification and intervention for children with emotional disturbances should be promoted by the system of care in order to enhance the likelihood of positive outcomes.
8. Children with emotional disturbances should be ensured smooth transitions to the adult-services system as they reach maturity.
9. The rights of children with emotional disturbances should be protected, and effective advocacy efforts for children and adolescents with emotional disturbances should be promoted.
10. Children with emotional disturbances should receive services without regard to race, religion, national origin, sex, physical disability, or other characteristics; and services should be sensitive and responsive to cultural differences and special needs.

From: Stroul, B. & Friedman, R. (1986). Washington, DC: Georgetown University Child Development Center.

Principles for Family Involvement, Federation of Families for Children's Mental Health

Families define themselves and their own culture.

Families require culturally competent services and supports reflecting their race, ethnicity, gender orientation, language, socio-economic background, and family structure.

Families have their basic needs met.

Families identified priorities and concerns drive policy and practice.

Families share power to make decisions and responsibility for outcomes.

Families and their system partners know their individual strengths, limitations, and fears.

Families have their own independent organization to speak with a collective voice for system change.

Families and their organizations get both respect and protection from their system partners.

Federation of Families for Children's Mental Health

1101 King Street, Suite 420 Alexandria, VA 22314

Phone: 703-684-7710

Full List of Recommendations from Each Workgroup

Each workgroup developed several recommendations for action steps related to incorporating or strengthening family voice in policy and practice regarding the issue discussed in their group. In the interest of “banking” all the excellent ideas that emerged from each discussion, the full lists of recommendations from each group are in the tables below. Only minor editing has been done for readability. Otherwise, the recommendations are listed here *as they were stated in the workgroup*. The number of votes reflects the priority setting process of the workgroup. The top two recommendations receiving the greatest number of votes (three if they were tied) are included among the final recommendations emerging from the Summit.

RESPIRE CARE

This workgroup developed recommendations for improving opportunities for family voice in the quantity and quality of respite care.

# VOTES	RECOMMENDATIONS
8	Line item written in the [state] budget
5	Bring families together in a forum (e.g. CASSP/LCC/Support groups) to define the needs; use forum to train families to advocate/be a voice; bring legislators to the families in the family-friendly forum (e.g. in support groups)
4	Make meeting times family friendly
4	School districts need to be more involved in informing parents – concrete steps to working with parents; the statewide special education is creating a subcommittee to get families more involved
2	Parent volunteer training – recruiting participation to get voices heard – giving back
1	Make respite “the norm” – prescription for respite
1	Subcommittee focused on Project Hope enhancement \$\$
1	Outreach campaign – materials in different languages, information, how to get them [families] involved; reach a diverse population
1	Ask parents to participate
0	Advocacy at administrative levels – Respite Care Committee (Sharon Kernan)
0	Parent Involvement for grant \$ -- Feasibility study
0	Get Local Coordinating Councils involved in the feasibility study
0	Mom’s club
0	\$ funding for kids with severe disabilities

FAMILY CENTERED NEIGHBORHOOD BASED SERVICES

This workgroup focused on family voice in designing and implementing neighborhood-based services.

# VOTES	RECOMMENDATIONS
5	Enhance the utility of the system (LCC/CASSP model)
3	Address the need of families to be a part by way of developing a family-to-family mentoring
2	Allow LCC to create subcommittees as needed (i.e. resource teams, parent advisory)
2	Building partnerships
2	Identifying and providing community-based services earlier
2	Move the process into the already existing system; committee to become part of existing LCC
2	Support resources for community and families for the long haul and expand community outreach (to meet needs of community)
2	True collaboration/power sharing and accountability from DCYF to promote practices
1	Communication of shared vision and method of moving forward
1	Early assessment and intervention
1	Educational trainings and setting standards
1	Form better relationship between public sector and private sector
1	Listen to parents sitting at the table
1	Lobby for funding mechanism for all children, not only children in DCYF care
1	More focus groups pairing pro-social youth with youth having challenges
1	Utilize provider contracts
0	Assist LCCs in efforts to build stronger partnerships, collaborations, and networks
0	Attack the language barrier
0	Better coordinated planning with policy (systems level)
0	Building and strengthening LCC to be more reflective of community
0	Cultural competency woven in at all levels
0	Establish relationship over time (go back to the community and redevelop partnerships)
0	Invest more in conjoint training for public/private sectors
0	More participation from parents about community issues
0	Parent support groups involved at community level
0	Retool CASSP (to address a broader range of mental health needs across families)
0	Training and support groups to enhance their effectiveness

TRANSITIONS

This workgroup examined ways including family voice in helping youth and their families transition from the world of children’s services to that of adult services.

# VOTES	RECOMMENDATIONS
17	Start planning early – before [child is] 18 years old
15	Support groups for parents of children in transition
7	Community involvement, mentoring at 14, open up opportunities for employment;
7	Talk about mental health and transition issues early
4	Create a welcoming culture in schools
2	Address liability issues
2	Orient services toward family involvement
1	Add transition plan to IEP
1	As a parent, never give up – unconditional love
1	Help child maintain existing relationships
1	Make participation accessible – time of IEP meetings, compensated participation in conferences
0	Many agencies in Providence’s South Side are open to volunteers
0	This mission statement is something we believe in

FAMILY INVOLVEMENT IN POLICY DECISIONS FOR FUNDING

This workgroup reflected on both strengths and weaknesses of the current system and points of opportunity for family voices to be heard in decision making about funding.

# VOTES	RECOMMENDATIONS
10	Incorporate family members as leaders (and voting members) within the Children’s Cabinet. Parent representative from each of the state departments should serve on the Children’s Cabinet
10	Conduct an organizational self-assessment to determine policies, structures, and practices that hinder family engagement (including cultural and linguistic competency) and change them. This was suggested by Tawara Goode from the National Center for Cultural Competence at Georgetown University; they have a method by which this could be done
8	Institutionalize policies and practices for incorporating family voice into policy and financing. We are starting to hear core values from multiple departments – need to institutionalize these beginning practices through departmental changes and/or legislation

FAMILY INVOLVEMENT IN POLICY DECISIONS FOR FUNDING (CONTINUED)

# VOTES	RECOMMENDATIONS
8	We want parent involvement across the system – Have all state certification standards include a requirement for family governance – it is critical that provider agencies take this role as well as the state agencies themselves.
6	Include parents on policy bodies. Review recruitment policies to more effectively recruit a broad range of parents (so that you don't end up missing the perspectives of groups, communities, people of diverse racial, ethnic, language, socio-economic backgrounds). Must get more minority families to the table. Need to address the needs of minority families. Families need to see people who look like them in leadership positions. This will increase their comfort level and make them feel they are being listened to.
6	Create linkages with schools so that there are partnerships among parents, schools, and state agencies. Do this by working with groups that are already working with parents. Some agency has to take the lead to develop this collaborative group. Need public policy supports – such as from the Governor and the General Assembly – in order to add leverage and credibility.
5	Develop clear values and principles for family engagement and community engagement and involvement and operationalize through policies and guidelines in each department. State agencies need to look at own policies re: parent input into service design, especially when making funding decisions.
5	Invest in organized efforts involving multiple state agencies and parent and advocacy groups to support, train, develop, and sustain parent leadership; build on experience of current parent leaders, and recruit and support new leadership. Provide parents with the information and skills they need to be informed contributors to the policy and funding discussions.
4	Invest in partnership, teambuilding activities with staff, parents, youth, all state agencies. Do this in an ongoing way – this is a culture and value shift. System needs to invest in and actively support and sustain family and community engagement and leadership. It is a philosophical change that needs to be backed up with resources.
3	Develop and use a curriculum for youth and parents on how and when funding decisions are made and how they can effectively be involved in the process.
3	It is hard to get parents to meetings – need child care with trained professionals who can care for children with special needs
1	Need more coordination of parent voice across the state agencies. Consider streamlining the number of avenues for family involvement. Make it more effective with less duplication, share information across the different groups, have groups meet together periodically to share parent expertise and provide more support to parent leaders

FAMILY INVOLVEMENT IN POLICY DECISIONS FOR FUNDING (CONTINUED)

# VOTES	RECOMMENDATIONS
0	Provider community needs to involve parents
0	Mandate that the information from surveys of families and their needs are used when setting funding priorities.
0	Develop, publish, and distribute a newsletter – e-news, cassettes – to share family ideas, thoughts, etc. on children’s behavioral health – include range of perspectives (parents, family members, children, youth)
0	Need to blend funding streams, be flexible, create new services, create linkages across services. Health plans can accomplish many of the things we need to get done
0	Include a significant number of parents on boards of organizations, including health plans and service providers
0	DCYF needs to do more about promoting the positive aspects of the department – highlight the community-based supports that are available to support families
0	Advocate for all families with all needs with all kids – these recommendations are applicable across all issues of concern.
0	Community-based programs often have parent input, consumer advisory groups. Residential facilities tend to not involve parents and families as much. Need to have residential contractors do more with family involvement.
0	Need better coordination of funding across state agencies in the human services field. Develop a system that is more cost effective.
0	Need legislation and/or Executive Order to facilitate system reform for children, youth and families. Yet, also need to flexibility for state agencies to respond to needs appropriately in a timely, effective way.
0	Develop a long-range communications strategy to inform policymakers, the public, and others about the issues affecting children and families. Increase the overall level of awareness.
0	Fund training and education slots for providers and staff of direct-care service agencies about how to relate to families.
0	Partner with Parent Teacher Organizations to seek input regarding community needs, access issues; and integrate with parent feedback.

PROGRAM EVALUATION AND QUALITY ASSURANCE

This workgroup focused on the inclusion of family voice in program evaluation and quality assurance efforts by state and local agencies, organizations, and programs.

# VOTES*	RECOMMENDATIONS
X	Involve the family at intake
X	Improve physical access to services: transportation, interpreters, respite care
X	Develop a clear description of expected treatment outcomes for families to measure against
X	Agency-driven family involvement opportunities: Board of Directors, Quality Improvement Committee, Agency reviews (DCYF, JCAHO), Outcome Evaluation
	Talk about strengths first instead of weaknesses
	Redefine “family work” as work that occurs in the home and community
	Stop withholding family visits as a form of punishment
	Change the philosophy of the system to include the child and the family
	Increase the use of after-care
	Increase the use of data to inform system improvement
	Use periodic satisfaction surveys administered to youth and family members
	Establish measurable treatment goals that are agreed on by the family and entire treatment team
	Develop clear guidelines/protocols for services so that quality can be assessed
	Adapt to new issues that arise from clinical evaluations
	Use parent consultants to connect families to resources
	Provide youth with peer and professional support in the school setting
	Develop a standard for family involvement and include it in all contracts
	Ensure that feedback is responded to in a timely way
	Improve outreach/tracking/support when the child returns to the family
	Place a PSN parent advocate at each provider site
	Improve oversight for evidence-based practice
	Engage more than one “token” parent in program evaluation and quality assurance
	Involve parents in all aspects of agency operations (staff training, policy development, etc.)
	Recognize that parents vary in their desired level of involvement and accommodate different levels

**Vote count not available for this list. An X indicates recommendation was selected as a priority by the workgroup.*

Acknowledgements

Many thanks to Dr. Janet Anderson (DCYF), Cathy Ciano (Parent Support Network of Rhode Island) and to the Office of the Governor for their leadership in convening this Summit. Thanks also to Colleen Hedden, who worked tirelessly behind the scenes, Kathy Crowe, for her incredible skill at coordinating this event and its innumerable details, and to the Summit Planning Committee: Janice Pangman, Cheryl Santos, Abel and Guillermina Vasquez and youth members Peter, Anthony, Adrian, and James. I feel honored to have been invited to observe and document this first time event. Thanks as well to Bill Eyman, Facilitator Extraordinaire, who always inspires me to improve my own facilitation skills and to the staff of Rhode Island KIDS COUNT: Elizabeth Burke-Bryant, Cathy Walsh, Veronica Kot, Kat Pannhorst, Teresa Hancock, and Ramonde Charles. The KIDS COUNT staff not only served as wonderful facilitators for each of the five workgroups, but their notes and observations form the substance of the descriptions of those sessions contained in this document. (I couldn't be in five places at once!) A special thank you to Rebecca Chandler of Chandler Design for her creative development of all the print materials for this event, from the save-the-date postcards and invitations to the design and layout of this final report.

To the Co-Sponsors of this event, hats off to you for being true partners in system reform. To the many participants of the Summit – especially the youth, the family members, and the volunteers – a special thanks for your courage and passion which serve as an inspiration. As a result of this Summit, there is a more pronounced, collective determination that will ensure the voices of families are heard as true partners in system reform. Others who attended the event have reviewed this document carefully, but any errors are mine.

Andrea V. Ferreira

