

# PARENT ENGAGEMENT IN STATE POLICY AND PLANNING

A DIRECTORY OF OPPORTUNITIES FOR PARENTS  
TO GET INVOLVED IN STATE  
POLICY AND PLANNING

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# INTRODUCTION

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*Parent Engagement in State Policy and Planning* is an inventory of Rhode Island state agency efforts to involve parents in the design, implementation, evaluation and oversight of policy and programs that affect children and families in Rhode Island.

The report describes current efforts by state agencies in Rhode Island to incorporate parent perspectives. Information on these programs was provided by state agencies to Rhode Island KIDS COUNT in response to a survey. The report also provides information on ways to gain meaningful parent involvement and strategies that can be implemented to engage and sustain parent voices at the table.

This directory was compiled as part of Rhode Island KIDS COUNT's work with the *Family Assets Initiative* sponsored by the Ford Foundation. This directory is meant to serve as a starting point for discussion on how to involve parents in policy and planning. It does not include descriptions of the numerous other ways parents can become involved in community level advocacy or direct legislative advocacy.

Involving parents, listening to their perspectives and learning from their experiences can result in more responsive policies and programs that truly improve the lives of children and families across the state, particularly low-income children.

Rhode Island KIDS COUNT is a children's policy organization that provides information on child well-being, stimulates dialogue on children's issues and promotes accountability and action.



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# PARENT ENGAGEMENT IN PUBLIC POLICY

## THE IMPORTANCE

Parents and other family members give credibility to policy work by providing pragmatic, culturally relevant information from a unique perspective.<sup>1</sup> Parents have been the most underrepresented partners in policy deliberations, despite their wealth of firsthand knowledge of how child and family policies and programs work or do not work. Accessing this knowledge and experience is critical to shaping policies and programs that are responsive, appropriate, sensible and effective.

Parent concerns and insights are broad in scope and their perspectives can help to design and implement more effective programs and can help to reduce barriers to accessing services. A scarcity of parent involvement in policy and planning should not be considered a lack of parental interest, but rather should serve as a springboard for identifying barriers to participation that parents may face. Strategies are needed to bring parents into the decision-making process in a meaningful way. Policy group leaders often struggle to find parents and family members who are willing and able to make a commitment and sustain their involvement over time.

## FACTORS TO CONSIDER

Sincere and deliberate efforts must be made to improve the involvement of parents and to diminish barriers to participation. Simply asking parents to become involved is insufficient. Parents must feel like their input and involvement is meaningful and will result in change. Without meaningful involvement, parents who do engage in policy and planning groups are not likely to continue to devote their time and energy.<sup>2</sup>

Promising practices do exist that demonstrate successful methods for engaging parents in policy discussions. Recruiting parents in a significant manner requires finding common hopes and concerns among parents, providers and policy makers and involves asking parents what their needs are to even be able to participate.<sup>3</sup> State agencies need to make clear from the beginning the purpose of the policy group, the level of influence that parents can expect to have and projected accomplishments. Providing information about the policy group's mission, structure and membership requirements, if developed already, will help parents to make informed decisions about the best of use of their time. Additionally, state agencies can help parents to understand the potential costs for participation by clearly explaining time commitments, meeting locations and meeting schedules and what expenses if any will be covered.

State agencies can reach out to families in a variety of ways. Indirect methods for reaching families include contacting existing local agencies, groups or associations that support the mission of the policy group.<sup>4</sup> Examples of this approach include reaching out to statewide family organizations, such as the Parent Support Network, Parents for Progress, the Rhode Island Parent Information Network, Family Voices and others. Additionally, Rhode Island has a wealth of community and neighborhood-based organizations and leadership groups that can be engaged. More direct methods for building links with families include sponsoring and attending conferences, forums or public discussions concerning children. Direct recruitment of parents who are enrolled in existing programs can also be effective.

# PARENT ENGAGEMENT IN PUBLIC POLICY

## ADDRESSING THE BARRIERS TO PARENT PARTICIPATION

*Meeting times* - Most parents, particularly low-income working parents, are often unable to attend meetings during traditional business hours. Varying meeting times can accommodate different constituencies.

*Costs* - Unlike professionals, parents are rarely paid for their time and efforts. Parents should not incur expenses for volunteering to be a part of the process.

*Child Care* – Parents need quality care for their children, including those with special needs, if they are going to participate in policy and planning.

*Transportation* – Parents need access to reliable and convenient transportation in order to attend meetings, particularly for regional or statewide meetings.

*Number of Parents* – One or two parents in a meeting with professionals is more likely to doubt his or her knowledge and experience, stifling his or her ability to contribute to the discussion.

*Professional Jargon* – Using acronyms and overly technical language makes understanding and sharing information difficult.

*Training and Experience* – Parents do not always have the experience of working toward system change and may need training on advocacy, problem solving and public speaking. Professionals often need training to help them develop the skills needed to work effectively with parents.

Source: Weber, Roberta and Jerri Wolfe. (2002). *We Can't Get There Without Them: Addressing the Barriers to Parent Participation in Building America's Child Care System*. Oregon Child Care Research Partnership. Albany, Oregon: Linn-Benton Community College.

## OPTIONS FOR ENGAGING PARENTS

The following options are just some of the ways to engage parents in policy and planning work.

- *Parent Advisory Groups*: Enable parents to add their perspective as decisions are made.
- *Community Surveys*: Involve parents in the planning of community surveys and focus groups.
- *Leadership Training*: Identify and train parents to act as leaders in their neighborhood, city and state.
- *Public Speaking and Advocacy*: Provide occasions for parents to testify, present at conferences, speak to the media and meet directly with elected officials.

Source: Dichter, Harriet, and Nancy Sconyers. (February 2002). *Parent Engagement in the Context of Child Advocacy Organizations*. Unpublished paper. New York, NY: The Ford Foundation.

# CULTURAL AND LINGUISTIC COMPETENCE

## ENSURING COMPETENCE

√ Cultural and linguistic competence in policy and planning is critical as Rhode Island's population becomes more racially, ethnically and linguistically diverse. Changes to policies and planning in state government must meet the needs of these diverse populations. Community engagement and family-professional partnerships are critical elements in the design of effective programs and policies.

√ To be culturally competent organizations must have:

- Clearly defined values, behaviors, attitudes, policies, structures and practices.
- The capacity to value diversity, conduct self-assessment, manage the dynamics of difference, acquire and institutionalize cultural knowledge and adapt to the diversity of the communities they serve.
- The capacity to incorporate the above into all aspects of policy making, administration, practice and service delivery. The capacity to involve consumers and other stakeholders.

√ To be linguistically competent organizations must have:

- Bilingual/bicultural staff.
- Foreign language and sign language interpretation services.
- Assistive technology devices, such as hearing aids, audio amplifications, etc.
- Print materials in easy-to-read, low literacy picture and symbol formats.

Sources:

National Center for Cultural and Linguistic Competence. (2004). *Cultural and Linguistic Competence: Implications for Policy Development*. Presented by Tawara Goode at the Families as Partners in System Reform Summit sponsored by the Rhode Island Department of Children, Youth and Families in May 2004.

*Planning for Cultural and Linguistic Competence in Systems of Care for Children and Youth with Social-emotional and Behavioral Disorders and their families*. (2003). Washington, DC: National Center for Cultural Competence, Georgetown University Center for Child and Human Development.

## APPROACHES TO MEANINGFUL PARENT INVOLVEMENT

The following five principles are culturally and linguistically competent approaches to meaningful involvement of parents in system reform:

- Identify the strengths, needs, and help-seeking behaviors of families.
- Design, implement and evaluate services and supports.
- Respect that the family is usually the primary system of support.
- Uphold the right of families to make choices based on cultural beliefs or preferences.
- Respect, understand and provide support for the linguistic needs of families.

Source: National Center for Cultural and Linguistic Competence. (2004). *Cultural and Linguistic Competence: Implications for Policy Development*. Presented by Tawara Goode at the Families as Partners in System Reform Summit sponsored by the Rhode Island Department of Children, Youth and Families in May 2004.

# STRATEGIES FOR KEEPING PARENTS ENGAGED

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Sustaining parent engagement in policy and planning work is not an easy task given all the barriers that both professionals and parents face in developing effective partnerships. These challenges are not insurmountable. State agencies can take several steps once parents are engaged to maintain their participation.

First and foremost, state agencies need to be clear about the realities of the political and economic environment in which the work is being done and about the internal and external factors that will impact prioritizing and decision making. State agencies need to offer a clear explanation of what is being worked on and how it relates to the bigger picture. It is valuable to share data, including an explanation of where the data came from and what process was used to collect. All information needs to be presented in a format and a language that is easily understood by those outside of the bureaucracy. These steps will help parents and professionals to feel they have a true understanding of the issues and the work at hand. This knowledge will help parents to decide how to contribute to the work.<sup>5</sup>

State agencies can also offer training and support to parents so that they learn to trust and vocalize their personal experiences and be confident in their role as a critical voice at the policy table. Sitting in a room of professionals or “experts,” can be intimidating for parents, particularly if they are being asked to comment on a system or program that they rely upon for the care of their family. Parents may feel reluctant to openly criticize that system or program, regardless of how dissatisfied they are.

Parents who participate on policy groups often pay for that privilege with lost wages, travel costs, and meeting expenses or child care, whereas professionals are compensated to participate in the same activities. Equity at the table does not end with respecting and listening to the parent’s perspectives, but must also consider compensation for their time, accommodating meeting times and locations, as well as either paying for or arranging child care so their children are cared for while they participate.<sup>6</sup>

Finally, state agencies can work to validate and appreciate parent efforts of participation. To accomplish this, a formal record of group activities, the results, and any actions taken can be established. All member recommendations and decisions should be documented and when decisions are made there should be accountability for implementation or next steps.<sup>7</sup>

## BEYOND PARENT ENGAGEMENT

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Engagement in decision making is the first step toward improving the design of programs and the services provided. Inviting parents to learn about the programs, policies and planning process are critical to building a trusting relationship between providers and consumers. Taking this one step further, by involving parents in the policy and planning discussion by providing training and by acting on their advice, parents are encouraged to become active participants in the group.<sup>8</sup>

When parents can see that their efforts and input can effect change they become confident, articulate and successful advocates for children. Working side by side with professionals in the field, they move beyond involvement and become active leaders in the shaping of policies and programs not only in the policy group, but in their communities.

# OPPORTUNITIES FOR PARENTS TO GET INVOLVED

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What follows is a listing of selected state agency opportunities for parents to become involved in policy and planning decisions. The directory is a synthesis of information provided to Rhode Island KIDS COUNT through a survey of state agencies. The directory does not evaluate or indicate the level of parent partnerships beyond what was reported by the state agency departments. The directory is meant to be a starting point for parents who are interested in helping to develop effective programs and policies by contributing their experiences and perspectives.

## RHODE ISLAND DEPARTMENT OF HUMAN SERVICES

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### *CEDDAR Policy Advisory Committee*

CEDARR Family Centers are a one-stop location where parents can get information and support about physical, developmental, behavioral or emotional problems their children may be experiencing. CEDARR stands for Comprehensive Evaluation Diagnosis Assessment Referral and Re-evaluation. There are three CEDARR Family Centers that work with families across the state.

Focusing on parents and families of children with special needs, the CEDDAR Policy Advisory Committee was established in September of 2000 to ensure that CEDARR Family Centers promote a wider array of services focused on the family. This committee continually monitors CEDARR and their programs. Subcommittees are developed based on needs expressed by families.

This advisory committee will absorb the responsibilities of the Personal Assistance Services and Supports (PASS) Advisory Committee in providing feedback on the PASS program and its standards. The PASS program enables families of children with special needs to choose their own service providers to assist their children so that they are able to participate in a variety of community-based activities.

#### Number of Parents Involved:

Parents comprise a majority of this committee and hold a majority of the votes. Currently there are eleven parents involved, with 6 who are voting members.

#### *Highlights*

*A work group of the committee designed temporary services for families on waiting lists for Home Based Therapeutic Services.*

#### Meeting Details:

Meets the second Wednesday of every month from 4:00pm to 5:30pm at the Rhode Island Department of Human Services in Cranston, RI.

#### How to Get Involved:

Call Joanne Quinn, Executive Director, Autism Project of Rhode Island at 401-785-2666 to receive an application.

#### Other:

Offers a \$65 per meeting stipend.

# RHODE ISLAND DEPARTMENT OF HUMAN SERVICES

## *Head Start and Comprehensive Child Care Programs*

The Head Start Program and Rhode Island's Comprehensive Child Care Network provide low-income (up to 100% of the federal poverty level for Head Start and 108% of the federal poverty level for the CCCN) preschool children and their families with the skills they need in order for children to enter school ready to learn.

### Number of Parents Involved:

Varies by program.

### Meeting Details:

Head Start meetings are held at the centers or at the Administrative office. Comprehensive Child Care meetings are held at the central office or at a partner agency location.

### How to Get Involved:

Contact your local Head Start Center. For Comprehensive Child Care meetings, contact Susan Libutti at the Rhode Island Department of Human Services, 401-462-6881.

### Other:

A seat is reserved for a Head Start parent on RI's Child Care Commission, facilitating state level policy work outside of their local Head Start program.

## *Advisory Committee on Child Care and Development*

This committee gives child care providers, representatives from the Children's Cabinet and parents the opportunity to discuss policy and program changes designed to improve access, affordability and quality within the child care and early education system.

### Number of Parents Involved:

Varies

### Meeting Details:

Meetings are held monthly from 1:00pm to 3:00pm at the DHS, 600 New London Avenue, Cranston, RI. A few meetings per year are held in the evening at community based locations in order to provide an opportunity for parents to participate and voice concerns.

### How to Get Involved:

To get involved contact Reeva Sullivan Murphy, Child Care Administrator, DHS at 401-462-6875.

### Other:

Thirty dollar stipends are offered to cover participation costs and child care.

### ***Highlights***

*Parents are involved in decisions regarding the approval of the annual budget, the review of program assessments and the hiring of key staff.*

*Parents are involved in the approval of all changes to policies and procedures.*

### ***Highlights***

*Feedback is provided on proposed policy changes to the Child Care Assistance Program.*

# RHODE ISLAND DEPARTMENT OF HUMAN SERVICES

## *Welfare Reform Implementation Task Force*

Focusing on low-income parents and families who are eligible for and receive cash assistance from the Family Independence Program (FIP), this advisory committee was established in 1996 to assist the Department of Human Services (DHS) in implementing new state and federal welfare legislation. This Task Force also assists DHS in creating and building opportunities to help parents access needed education, training and employment so that they can become more economically secure and to assure that appropriate resources such as literacy, basic education and post secondary education resources are available. The task force ensures that family supports such as child care assistance, food stamps and transportation are offered to low-income families while they are working and/or preparing for work under welfare-to-work regulations.

Parents for Progress, a community based organization of parent volunteers, is an active member of this task force and its subcommittees and constitutes the parent voice at the table. During the legislative session, Parents for Progress meets daily or weekly, depending on the need and action plans. For more information on Parents for Progress, please see page twenty-four.

### Number of Parents Involved:

Parents generally attend the task force meeting during hot topic discussions, but they are also represented by a staff member of Parents for Progress.

### Meeting Details:

The task force itself meets the first Friday of every month from 9:00am to 11:00am at DHS, Amy Forand Building, 600 New London Avenue, Cranston, Rhode Island. Additional meetings are scheduled as needed.

### How to Get Involved:

To become involved in the task force contact Linda Katz, Policy Director of the Poverty Institute at 401-456-4634 or Donalda Carlson, Administrator, Individual and Family Support, Center for Children and Family Support Programs, DHS at 401-462-2423.

To become involved in Parents for Progress, contact Heidi Keezer, Executive Director of Parents for Progress at 401-780-6840.

### ***Highlights***

*As members of this task force, Parents for Progress makes recommendations to the Department about policy changes, including education of clients and dissemination of information. For example, Parents for Progress advised DHS of the need for a brochure on FIP produced in layman's terms that would be disseminated to consumers.*

*Parents for Progress' involvement on the housing subcommittee of the task force resulted in DHS allowing participant housing searches to count as an acceptable work activity under welfare-to-work.*

*Parents for Progress also provides valuable input on the letters and notices sent out to FIP participants.*

# RHODE ISLAND DEPARTMENT OF HUMAN SERVICES

## *Food Stamp Advisory Committee*

This advisory committee was established to advise the Department of Human Services (DHS) on food stamp access and policies and hunger prevention issues. The committee seeks to engage low-income parents and families in the discussion with DHS staff and community stakeholders about nutrition, public awareness and food stamp outreach efforts.

### Number of Parents Involved:

Parent participation ranges on average from 1 to 3 parents per meeting, with participants generally coming from the Community and Family Development Project, also at the DHS.

### ***Highlights***

*Policy recommendations are made on an ongoing basis. As a result of one recommendation, a new streamlined Food Stamp application is being developed, with feedback from the committee.*

### Meeting Details:

This committee meets the second Monday of every month from 10:30am to 12:00pm at DHS, Amy Forand Building, 600 New London Avenue, Cranston, RI.

### How to Get Involved:

For more information contact Kathleen Gorman, URI Feinstein Center for a Hunger Free America at 401-277-5450 or Bob McDonough, Administrator for Adult Services, DHS at 401-462-6837.

## *RItE Care Consumer Advisory Committee*

RItE Care is Rhode Island's Medicaid managed care program that provides eligible pregnant women, parents and children up to age 19 with comprehensive health insurance coverage. RItE Care also provides families enrolled in the Family Independence Program with health coverage. Established in 1994, the RItE Care Consumer Advisory Committee is made up of representatives from state agencies, the advocacy community, the research community, providers, health plans and families. This committee meets to discuss and provide feedback regarding issues, concerns and problems with RItE Care eligibility, quality and access to health care.

### Number of Parents Involved:

Most parent participants are involved through other capacities, such as working for an advocacy group.

### ***Highlights***

*The group has reviewed materials sent to RItE Care members from the health plans and the state, including an annual member satisfaction survey. The group also tracks community access barriers to RItE Care and problems with the application process.*

### Meeting Details:

Meets the second Thursday of every month from 10:00am to 12:00pm at the DHS, Simpson Hall, 600 New London Avenue, Cranston, RI.

### How to Get Involved:

For more information contact Marti Rosenberg, Ocean State Action Fund at 401-463-5368.

# RHODE ISLAND DEPARTMENT OF HUMAN SERVICES

## ***Early Intervention Interagency Coordinating Council***

Formed in response to Part C of the Individuals with Disabilities Education Act (IDEA), the Early Intervention Interagency Coordinating Council (ICC) advises the Department of Human Services in the planning, development and implementation of a statewide system of services for infants and toddlers with disabilities, as well as for at-risk infants and toddlers and their families, including transitions into the educational system.

### Number of Parents Involved:

There are currently 11 family representatives. Federal law requires that parents comprise at least 20% of the ICC.

### Meeting Details:

Meetings are held at various community sites from 9:30am to 12:30pm the third Thursday of every other month, or more frequently as needed.

### How to Get Involved:

Members are appointed by the Governor for two year renewable terms. Interested individuals can contact the ICC Chair, Dawn Wardyga at 401-727-4144 x158.

### Other:

Parent representatives receive a stipend for participating in the meetings.

***Highlights***

*Members of the ICC advise other state agencies on the integration of services and assist in the preparation of the EI Annual Performance Report that is submitted to the Governor and U.S. Department of Education.*

*The ICC helps to identify fiscal and other sources of support for Early Intervention (EI) system.*

*The ICC works with the Department of Education on the transition of toddlers with disabilities to preschool and other needed special education services.*

## ***Leadership Roundtable for Children with Special Health Care Needs***

Focusing on parents and families of children with special needs, this group was established in 1999 to help develop and evolve a family-centered, community-based system in Rhode Island. This committee serves as an advisory group to the Department of Human Services (DHS) and as a source of volunteers for focus groups.

### Number of Parents Involved:

Approximately 150 family members are on the Roundtable mailing list.

### Meeting Details:

The Roundtable generally meets quarterly, centered around the need for input on new matters.

### How to Get Involved:

To get on the mailing list, call Ruth Schennum, DHS, at 401-462-0137.

***Highlights***

*This group was the source of the initiative that resulted in CEDARR Family Centers and CEDARR direct services.*

*The Roundtable contributed to the design and implementation of the process for moving children with special health care needs from fee-for-service Medical Assistance to managed care.*

# RHODE ISLAND DEPARTMENT OF HUMAN SERVICES

## *Respite Care Committee*

Focusing on parents and families of children with special needs, this committee is expected to begin in the fall of 2004 to help the Department of Human Services (DHS) define respite and explore respite care availability in Rhode Island.

### How to Get Involved:

For more information call Sharon Kernan, DHS at 401-462-3392.

## *Focus Groups*

The Department of Human Services sponsors ad hoc focus groups to gather perspectives from participants in the Child Care Assistance Program on child care services. Between November 2000 and May 2001, 17 focus groups were held. Additional focus groups will be held as needed.

### Number of Parents Involved:

A total of 215 individuals participated.

### Meeting Details:

Focus groups are conducted during evening hours.

### How to Get Involved:

To get involved, contact Reeva Sullivan Murphy, Child Care Administrator, DHS at 401-462-6875.

### Other:

Thirty dollar stipends are offered.

### ***Highlights***

*Contact information for Options for Working Parents, Rhode Island's Child Care Resource and Referral Network, is displayed on nearly all letters and mailings sent out regarding the Child Care Assistance Program.*

*An automated program recertification process was implemented to minimize complications for families applying for child care subsidies.*

# RHODE ISLAND DEPARTMENT OF HEALTH

## *Parent Consultant Program at HEALTH*

Managed by the Rhode Island Parent Information Network, this program involves parents and family members of a child who is currently or has been, within the last three years, enrolled in a Division of Family Health (DFH) program. The Parent Consultant Program at HEALTH ensures that parents are involved in program assessment, planning, implementation and quality assurances for all Family Health programs at the Rhode Island Department of Health. The program trains Parent Consultants to be effective advocates for families and informed spokespersons for the Maternal and Child Health programs. Parent Consultants use their knowledge and training about resources and services in Rhode Island to educate, advocate and assist families in accessing community resources. Parent Consultants also work to increase program utilization among eligible hard-to-reach populations.

Parent Consultants work 20 hours per week in a variety of program placements at the Department of Health. Training provided to parents include: leadership development; computer skills; how the legislative process works; focus group and facilitation skills; effective advocacy skills; and individual program skills depending on placement.

### Number of Parents Involved:

There are currently five Parent Consultant positions.

### Meeting Details:

Supporting activities from the Department of Health for the Parent Consultants include: individual meetings with parents; biweekly parent consultant meetings; and quarterly mentor meetings and trainings.

### How to Get Involved:

For more information, contact Adriana Leon, Program Director at 401-222-4637.

### Other:

Parent Consultants are paid positions with training, vacation, sick, holiday and personal time.

### ***Highlights***

#### *The Parent Consultant Program:*

- *Trains parents to advocate from a consumer perspective as policy decisions are made.*
- *Gathers parent input on program development, evaluation, case reviews and educational materials.*
- *Facilitates Parent Consultants serving as mentors for other families.*
- *Engages in community outreach by:  
    *Conducting parent satisfaction surveys.*  
    *Hosting community meetings and events.*  
    *Educating families and providers about programs.**
- *Works toward building interagency collaboration.*

#### *Examples of programs that Parent Consultants are engaged in:*

- *Immunization Program*
- *Lead Prevention Program*
- *Adolescent and Youth Unit*
- *Women, Infants & Children Program*
- *Parents as Partners Project*
- *Successful Start*

# RHODE ISLAND DEPARTMENT OF HEALTH

## *Parent Consultant Program, Pediatric Practice Enhancement Project*

Focusing on parents of children with special needs, this project is run by the Rhode Island Parent Information Network and was established in 2002 as a collaboration between the Rhode Island Department of Health (DOH), the Rhode Island Department of Human Services (DHS) and the Rhode Island Chapter of the American Academy of Pediatrics (AAP). The collaboration aims to improve access, availability, adequacy, appropriateness, accountability and effective administration of all services and supports to children with special health care needs. This project supports the Pediatric and Family Practitioners who provide primary care for children with special health care needs by assigning Parent Consultants to seven practices across the state to assist medical personnel and families in accessing CEDARR Family Centers and other community resources.

### Number of Parents Involved:

There are currently seven Parent Consultants working with Pediatric and Family Practitioners.

### Meeting Details:

Program meetings are held weekly. Steering committee meetings are held quarterly.

### How to Get Involved:

For more information, contact Linda McMullen at the Rhode Island Parent Information Network at 401-727-4144 x129.

### ***Highlights***

*The Pediatric Practice Enhancement Project of the Parent Consultant Program was designed and initiated by a team of parents and professionals. Daily supervision and implementation of the project is conducted by parents.*

## *Parent Consultant Program, Early Intervention*

Focusing on parents of children ages birth to three with developmental delays, the Parent Consultant Program, Early Intervention (EI), is managed by the Rhode Island Parent Information Network with funding from the Department of Health and Department of Human Services. Parent Consultants are placed in all eight of the Early Intervention sites to participate in the development of EI Policy and Procedures. EI Parent Consultants help to provide support and education to families to empower them to become knowledgeable participants and advocates. EI Parent Consultants also provide support and education to professionals on available resources for families.

### Number of Parents Involved:

There are currently twelve Parent Consultants working with Early Intervention programs across the state.

### How to Get Involved:

For more information, contact Lisa Schaffran at the Rhode Island Parent Information Network at 401-727-4144 x153.

### ***Highlights***

*EI Parent Consultants organize and facilitate regional parent groups and parent-to-parent workshops.*

*EI Parent Consultants were an integral part of the State Improvement Plan for Early Intervention and Special Education.*

*EI Parent Consultants helped establish funding to increase the role of the father/male caregivers in EI.*

# RHODE ISLAND DEPARTMENT OF HEALTH

## *Parent Consultant Program, Child Development Center*

Focusing on parents of children with special health care needs, the Parent Consultant Program, Child Development Center (CDC), is managed by the Rhode Island Parent Information Network with funding from the Department of Health and Hasbro Children's Hospital. The CDC provides interdisciplinary, comprehensive care for children with motor, cognitive, genetic, communicative and learning disorders.

CDC Parent Consultants ensure that the referrals are processed in a timely fashion and support families through the evaluation process by answering questions and providing information on disabilities and support services. CDC Parent Consultants also assist physicians and CDC staff on how to understand the unique perspective of a parent whose child is being evaluated and may have special needs.

### Number of Parents Involved:

There are currently two Parent Consultants working with the CDC Program.

### How to Get Involved:

For more information, contact Lisa Schaffran at the Rhode Island Parent Information Network at 401-727-4144 x153.

### ***Highlights***

*CDC Parent Consultants assist families in accessing specialty evaluations or specialty services and provide family support to those in crisis.*

*CDC Parent Consultants organized and streamlined the intake process - children are now being scheduled for assessments in a timely manner.*

*CDC Parent Consultants conduct Family Surveys based on Family Centered Services and Supports.*

## *Parent Consultant Program, Neonatal Intensive Care Unit*

Focusing on parents of newborn infants with significant medical problems, the Parent Consultant Program, Neonatal Intensive Care Unit, is managed by the Rhode Island Parent Information Network with funding from the Department of Health. The Parent Consultants, Neonatal Intensive Care Unit (NICU), provides support for families whose infant may be low birth weight, premature, suffer from birth defects and other problems requiring surgical intervention in the early newborn period.

### Number of Parents Involved:

There is currently one Parent Consultant working with the NICU at Women and Infants Hospital.

### How to Get Involved:

For more information, contact Lisa Schaffran at the Rhode Island Parent Information Network at 401-727-4144 x153.

### ***Highlights***

*The NICU Parent Consultant coordinates information events for families, assists staff in providing NICU orientation, develops and maintains support groups for the families, provides resources and referrals and provides support in the infants' transition home.*

# RHODE ISLAND DEPARTMENT OF HEALTH

## ***Parent Consultant Program, Office of Families Raising Children with Special Health Care Needs***

Focusing on parents of children with special health care needs, the Parent Consultant Program, Office of Families Raising Children with Special Health Care Needs (CSHCN), is managed by the Rhode Island Parent Information Network with funding from the Department of Health. CSHCN Parent Consultants participate in developing policies concerning Children with Special Health Care Needs and serve as advocates for family centered practice in human services.

### Number of Parents Involved:

There is currently one Parent Consultant working with the Office of Families Raising Children with Special Health Care Needs.

### How to Get Involved:

For more information, contact Lisa Schaffran at the Rhode Island Parent Information Network at 401-727-4144 x153.

### ***Highlights***

*The CSHCN Parent Consultant provides feedback to the Chief of the Office of Families Raising Children with Special Health Care Needs at the Department of Health.*

*CSHCN Parent Consultants developed a hearing guide for families in collaboration with the Rhode Island Hearing Assessment Program.*

## ***Parent Consultant Program, Community Asthma Programs of Hasbro Children's Hospital***

Focusing on parents of children with asthma, the Parent Consultant Program, Community Asthma Programs of Hasbro Children's Hospital is managed by the Rhode Island Parent Information Network with funding from the Department of Health and Hasbro Children's Hospital. Parent Consultants at the Asthma Programs assist families in developing the knowledge, motivation and skills needed to advocate for their children's health and successfully manage their children's asthma.

Parent Consultants at the Asthma Programs provide feedback to the Asthma Program Coordinator on the strengths and needs of the program and provide referrals to families who need support.

### Number of Parents Involved:

There are currently two Parent Consultants working with the Community Asthma Programs of Hasbro Children's Hospital.

### How to Get Involved:

For more information, contact Lisa Schaffran at the Rhode Island Parent Information Network at 401-727-4144 x153.

### ***Highlights***

*Parent Consultants at the Community Asthma Programs recruit families for workshops and education programs, coordinate workshops in English and Spanish, and staff the registration at the workshops.*

*Parent Consultants at the Community Asthma Programs follow-up with families to monitor participation and track and coordinate data on family and professional participation.*

# RHODE ISLAND DEPARTMENT OF CHILDREN, YOUTH AND FAMILIES

## *Youth, Parent, DCYF Partnership*

Focusing on parents, youth and families who are caregivers or relatives of children with behavioral health issues, this partnership was established in 2002 to ensure the development of an organized system of care for children and youth with serious emotional and behavioral health challenges. This partnership supports strengthening family and youth involvement in DCYF and strives to ensure that the further development and reform of a statewide system of care is consumer and family driven.

### Number of Parents Involved:

There are approximately 20 parents, grandparents, siblings, etc. and approximately 8 to 10 youth involved in this partnership annually.

### Meeting Details:

Full group meetings are held quarterly (September, December, March and June) at the John Hope Settlement House. Meetings are held in the evening.

Issue focused subcommittee meetings are held weekly to monthly, depending on the goal.

### How to Get Involved:

To become involved in this partnership, contact Brenda Alejo, Family Leadership Coordinator, at the Parent Support Network, 401-467-6855.

### Other:

Stipends and food are provided for each meeting.

### ***Highlights***

*This partnership worked to identify needs of the group and consequently provided training to youth and parents on how youth and families can effectively become involved in policy making.*

*In addition to beginning the relationship building and breaking ground on youth and parents as DCYF partners, the committee has formed three subcommittees:*

*Children's Behavioral Health Summit:* *This subcommittee worked collaboratively with DCYF on planning the annual Summit in May of 2004 with a focus on families' voices in policy and planning.*

*Respite Programs:* *This subcommittee is working to develop a shared definition of what respite care is for this population and what types of respite should be available. DCYF will incorporate this into a Request for Proposals (RFP) process, resulting in the delivery of adequate respite services for families.*

*Outpatient Services:* *This subcommittee is working with the Rhode Island Parent Information Network and Family Voices to update the Family Voices Resource Guide to be more responsive to the needs of parents of children with behavioral health issues.*

# RHODE ISLAND DEPARTMENT OF CHILDREN, YOUTH AND FAMILIES

## *Foster Parents Association*

The Rhode Island Foster Parents Association provides education and other forms of support to families providing substitute care, and to the community at large, in order to the well-being of children who cannot live with their parents.

This separate 501(c)(3) organization advises the Department of Children, Youth and Families (DCYF) on policies and procedures related to foster care.

### How to Get Involved:

To become involved, contact Lisa Guillette, Director of the Foster Parents Association at 401-781-1915.

### ***Highlights***

*In its advisory capacity to DCYF, this association comments on current policies and anticipated changes. This association also hosts an annual foster parent town meeting to encourage and recruit new foster parents.*

## *Project Hope Implementation Team*

Focusing on consumers and parents/caregivers of youth with serious emotional disturbance (SED) this project was established in 1999 to advise the Department of Children, Youth and Families (DCYF) on all policies regarding the transition of youth ages 12-22 with SED from the Rhode Island Training School to the community.

### Number of Parents Involved:

There is a consistent presence from the Parent Support Network and family members.

### Meeting Details:

This committee generally meets the third Thursday of every month from 1:00pm to 3:00pm. Meetings are usually held at the Rhode Island Council of Community Mental Health Organizations.

### ***Highlights***

*Project Hope engages youth and their families in planning and implementing transition services 90 to 120 days before the youth leaves the Training School.*

*This committee has helped to shape the overall program from the initial grant to the present day.*

### How to Get Involved:

Contact Brenda Almeida at the Behavioral Health Division, DCYF at 401-528-3759.

## *Care Management Teams*

The Care Management Teams are designed to involve a child's family in planning for treatment and service needs. The goal is to ensure that the necessary treatment is provided to maintain a child within their community whenever possible. Community based teams work with families to make treatment and service decisions within each of the Department of Children, Youth and Families (DCYF) regions. Services are provided to families with children and youth who are at high risk and who require a combination of services to effectively transition to or from residential treatment.

### How to Get Involved:

Contact Linda Essex, Assistant Administrator at DCYF, 401-528-3766 for more information.

# RHODE ISLAND DEPARTMENT OF EDUCATION

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## *Parent Engagement Action Team*

Focusing on all parents, this statewide advisory committee is currently being established to create a comprehensive system for increasing parent involvement and engagement in local schools. This action team will provide targeted technical assistance and guidance to local school districts about how to engage and retain parent involvement.

### How to Get Involved:

The initial action team members will be working to develop a process for parent engagement in the team. For more information, contact Virginia da Mota at the Rhode Island Department of Elementary and Secondary Education at 401-222-4600 x 2373.

## *Rhode Island Special Education Advisory Committee*

Focusing on parents and families of children with special needs, this advisory committee was established in the 1970's in response to Part B (serving children ages 3 to 21) of the federal Individuals with Disabilities Education Act (IDEA) to ensure input on policy issues and to monitor implementation of special education regulations. This committee is a well-established group at which parents' perspectives can shape public policy.

### Number of Parents Involved:

The majority of this committee are parents or family members.

### Meeting Details:

This committee meets monthly, plus one annual meeting. Meetings are held on the third Thursday of each month from 6:30pm to 8:30pm at the New England Institute of Technology in Warwick.

### ***Highlights***

*This committee serves as an oversight of special education in Rhode Island and looks at state and federal requirements, reviews problems and concerns, and conducts hearings to update regulations. Periodically, members of the committee attend local special education advisory meetings.*

### How to Get Involved:

Anyone wishing to get involved can apply. There is an interview process and appointments are made by the Commissioner of Education. To find out more, contact Jane Keane, Office of Special Populations at the Rhode Island Department of Elementary and Secondary Education at 401-222-4600.

# RHODE ISLAND DEPARTMENT OF EDUCATION

## *State Advisory Council for Limited English Proficient Students*

Focusing on parents of limited English proficient students, this advisory committee was established in 1982 to advise the Commissioner of Education on matters pertaining to English language learners. This committee focuses on both regulations and policy.

### Number of Parents Involved:

Statute requires three parents be involved. The council has established three year terms.

***Highlights***  
*Every three years (more if necessary) the council reviews regulations and recommends changes. This council also reviews federal requirements and changes.*

### Meeting Details:

This council meets four times per year, usually late in the afternoon (3:00pm to 5:00pm) or in the evenings. Meetings are held at the Rhode Island Department of Elementary and Secondary Education.

### How to Get Involved:

The Department of Education solicits input from local school districts and advertises in the paper when a seat is open. People can self-nominate. Members are appointed by the Commissioner. To find out more, contact Tom DiPaola, Office of Special Populations at the Rhode Island Department of Elementary and Secondary Education at 401-222-4600.

## *Progressive Support and Intervention Advisory Committee*

The Progressive Support and Intervention Advisory Committee focuses on parents and families from schools in need of improvement and subject to Progressive Support and Intervention. This advisory committee is in the process of being formed. This committee provides advice regarding intervention strategies to support districts with schools that are in need of improvement.

### Number of Parents Involved:

Three parents serve on this committee of 25 people.

### Meeting Details:

The committee is expected to be a permanent body meeting four times per year. Meetings are held at the Rhode Island Department of Education. Every effort is made to hold meetings during “family friendly” hours.

### How to Get Involved:

The advisory committee will be establishing a nominating process. For more information, contact David V. Abbott, Assistant Commissioner at the Division of Support Services at the Rhode Island Department of Education at 401-222-4600.

# RI DEPARTMENT OF MENTAL HEALTH, RETARDATION AND HOSPITALS

## *Governor's Council on Behavioral Health*

Focusing on families of adults with serious mental illness (SMI) and children with serious emotional disturbance (SED), the Rhode Island Governor's Council on Behavioral Health was created by statute in 2002 to advise the Governor and the Department of Mental Health, Retardation and Hospitals (MHRH) on issues relating to behavioral health. This council reviews and evaluates the behavioral health system's strengths and needs in Rhode Island. It also stimulates and monitors the development, coordination and integration of statewide behavioral health services.

There are 18 publicly appointed members of the council who represent a wide range of interests throughout the state in accordance with federal block grant requirements. Other members include the Rhode Island Mental Health Advocate, the Director of the Drug and Alcohol Treatment Association of RI, the President of the RI Council of Community Mental Health Organizations, the Director of the Department of Children, Youth and Families, Human Services, Corrections, Education, Health, Elderly Affairs, MHRH, the Attorney General and The Governor's Justice Commission.

### Number of Parents Involved:

Of the eighteen public appointments on the Council, there are three parents of children with serious emotional disturbance and two parents of adults with serious mental illness.

### Meeting Details:

The council meets monthly alternating between the second Tuesday and second Thursday of every month at 8:30am or 1:30pm in Barry Hall at the MHRH.

Meetings are open to the public.

The meeting schedule is posted on the web at

[www.mhrh.state.ri.us/  
governor\\_council\\_bh/  
2004meeting\\_schedule.htm](http://www.mhrh.state.ri.us/governor_council_bh/2004meeting_schedule.htm).

### How to Get Involved:

Contact Corinna Roy, Behavioral Health Planner, Department of Mental Health, Retardation and Hospitals at 401-462-0455.

### *Highlights*

*Shortly after the Council was formed, its members identified several behavioral health issues during a series of meetings. Members prioritized these issues and have organized themselves into three subcommittees to tackle them. One subcommittee report was essential in helping to create a new way of contracting for hospital beds in Rhode Island.*

*One subcommittee reviewed the "Systems of Care Task Force Report," a planning guide for services to children and families across state departments, and made recommendations related to its strengths and weaknesses in serving Rhode Island's youth.*

*The other two subcommittees are preparing reports for the upcoming legislative session:*

- *One report will identify the best way to serve high-end mental health service users (typically those using hospital beds) who also have contact with the criminal justice system and/or substance abuse.*
- *The other report will identify ways to overcome barriers that clients face accessing appropriate services.*

# RI DEPARTMENT OF MENTAL HEALTH, RETARDATION AND HOSPITALS

## *Prevention Task Forces*

In 1987, the General Assembly enacted the Rhode Island Substance Abuse Prevention Act (RISAPA) to promote comprehensive prevention programming at the community level.

Participating communities are required to have an active community coalition or task force with volunteer members who represent various community stakeholders, including: parents and students; school personnel; police and social service agencies; and religious and civic organizations.

The goals of RISAPA are: to promote the opportunity for municipalities to establish a comprehensive substance abuse prevention program addressing the specific needs of each individual municipality; to encourage the development of partnership among municipal governments, school systems, parents and human service providers to serve the interest of the community in addressing the need for a comprehensive substance abuse prevention program; to promote a substance abuse prevention program in every community; to encourage municipal governments, in cooperation with school systems and human services organizations, to jointly assess the extent of the substance abuse problem in their community; and to provide financial assistance for the planning, establishment and operation of substance abuse prevention programs.

### Number of Parents Involved:

There are thirty-four active RISAPA task forces. The number of parents represented varies by task force. Each task force has at least one parent representative.

### Meeting Details:

RISAPA meet a minimum of eight times per year. Each task force maintains its own meeting schedule, available from the respective task force Coordinator.

Task force meetings are open to the public.

### How to Get Involved:

Contact Bette Ann McHugh, Public Health Promotion Specialist at 401-462-5686.

### ***Highlights***

*RISAPA task force members generate, on average, more than 1,000 volunteer hours annually.*

*Task forces are required annually to develop and implement a prevention program service plan based on an assessment of community needs.*

*Task forces plan, coordinate and implement a variety of prevention initiatives including:*

- *Parenting workshops.*
- *Presentations at Parent Teacher Association or Parent Teacher Organizations.*
- *After-school programs.*
- *Programs for the elderly on the proper use of prescription medications.*
- *Advocacy for passage of State laws and municipal ordinances reducing youth exposure to alcohol, tobacco and other drugs.*
- *Promotion of proven effective prevention programs in the schools.*

# RI DEPARTMENT OF MENTAL HEALTH, RETARDATION AND HOSPITALS

## *Board of Directors for Community Based Behavioral Healthcare Agencies*

Under new licensing standards filed by the Department of Mental Health, Retardation and Hospitals (MHRH), a joint license for mental health and substance abuse services is now in place for community-based agencies. The purpose of this joint license is to better integrate the treatment and prevention of co-occurring disorders. One of the essential requirements of this license is that the Board of Directors of these agencies must have at least one consumer and/or family member.

The Board of Directors is responsible for assuring the quality of treatment services as well as the ethical standards and performance level of the agency. The Board also has primary responsibility for the fiscal management of the agency.

To ensure that the voices of parents and/or families are a part of the discussion, the standards require the Boards to include persons who have currently or formerly received behavioral health services, family members of persons who have received behavioral health services and persons living or working in the primary community served by the organization.

### Number of Parents Involved:

The number of parents and/or family members involved varies from agency to agency.

### Meeting Details:

Varies.

### How to Get Involved:

Contact James McNulty, at the Division's Office of Consumer and Family Affairs, MHRH at 401-462-0130.

### ***Highlights***

*The Board of Directors shall insure that each person receiving services has the right to self-determination and self-management of their illness.*

# RI DEPARTMENT OF MENTAL HEALTH, RETARDATION AND HOSPITALS

## *Enforcing Underage Drinking Laws Advisory Committee*

In 1999 the Enforcing Underage Drinking Laws Program (EUDL) was established by the U.S. Congress under the Appropriations Act. The purpose of the program is to support and enhance state efforts to enforce laws prohibiting the sale of alcohol to or the consumption of alcohol by minors. The Department of Mental Health, Retardation and Hospitals (MHRH), through the Division of Behavioral Healthcare Services, is the designated state agency to receive and administer the \$360,000 EUDL grant on behalf of Rhode Island. The Enforcing Underage Drinking Laws Advisory committee was established to help Rhode Island learn about the weaknesses in its existing underage drinking laws and help advocate for change in these laws.

The advisory council includes: a parent and victim advocate; representatives from both state and local law enforcement; Mothers Against Drunk Driving.; the RI Council on Alcoholism and Other Drug Dependence; the Governor's Office on Highway Safety; RI Family Court; Student Assistance; the RI Teen Institute; RI Hospital Injury Prevention; Substance Abuse and Prevention Task Forces; a university member and liquor retailer; and the Departments of the Attorney General, Education, Human Services, Health, Business Regulation and Children, Youth and Families.

### Number of Parents Involved:

Parents are involved directly on the committee and indirectly through policy, lobbying and outreach. This outreach enlists the support of parents to sign petitions and testify at legislative hearings related to policy changes that enhance the laws against underage drinking.

### Meeting Details:

Meets quarterly

### How to Get Involved:

Contact Brenda Amodei at 401-462-6085.

### ***Highlights***

*The council has reviewed several best practices in reducing underage drinking provided by the Office of Juvenile Justice and Delinquency Prevention (OJJDP) and has implemented several of them. The state received an award for innovation and perseverance in reducing underage drinking at OJJDP's National Leadership Conference for its work with law enforcement agencies, particularly those in the college communities of Newport and South Kingstown which have created a partnership with local liquor establishments to work together to address problems with fake identification.*

*Passed Keg Registration Law which is a keg labeling process that gives police a tool to trace a keg to the purchaser if that keg is made available to underage persons.*

*Passed law to increase fines and revoke the license of an underage person caught possessing alcohol.*

*Passed Mandatory Alcohol Server Training Law which reduces the likelihood that a bar or restaurant worker will serve alcohol to a minor.*

# RHODE ISLAND PARENT ADVOCACY GROUPS

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The following are examples of parent advocacy groups in Rhode Island that work with state policy and planning. Many more groups also work to improve state policies and/or do community level organizing and advocacy.

## Family Voices

Family Voices at the Rhode Island Parent Information Network is part of a national network of families and friends of children with special health care needs, including those with chronic illnesses and disabilities. Family Voices informs families and professionals about public and private health care changes in our state and the nation. They share the expertise and experiences of families with policy makers, the media, health professionals and other families. Family Voices advocates for health care services that are family-centered, community-based, comprehensive, coordinated and culturally competent. Family Voices promotes the inclusion of families as decision makers at all levels of health care and supports essential partnerships between families and professionals.

Dawn Wardyga  
Program Director  
401-727-4144 x158  
[familyvoices@ripin.org](mailto:familyvoices@ripin.org)

## Parents for Progress

Parents for Progress is a community-based organization of parent volunteers that is actively involved in policy and planning work within state agency departments and is also engaged in advocacy at the state house. Parents for Progress hosts ongoing community action events throughout the year, including: voter registration activities, expansion of support for families, educational access and parent education forums.

Heidi (Keezer) Collins  
Executive Director  
401-780-6840  
[pforprogress@aol.com](mailto:pforprogress@aol.com)

# RHODE ISLAND PARENT ADVOCACY GROUPS

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## Parent Support Network of Rhode Island

The Parent Support Network (PSN) of RI is an organization of families supporting families with children and youth who are at risk for or have serious behavioral, emotional and/or mental health challenges. The goals of PSN are to:

- Strengthen and preserve families.
- Enable families in advocacy.
- Extend social networks, reducing family isolation.
- Develop policy and systems of care.

Parent Support Network accomplishes these goals by (a) providing advocacy, education and training; (b) promoting outreach and public awareness; (c) facilitating social events for families; (d) participating on committees responsible for developing, implementing and evaluating policies and systems of care.

Cathy Ciano  
Executive Director  
401-467-6855  
[psnofri@aol.com](mailto:psnofri@aol.com)

## Rhode Island Parent Information Network

The Rhode Island Parent Information Network (RIPIN) is a statewide, nonprofit agency that provides information, training, support and advocacy for parents seeking help for their children. RIPIN is the home of four program areas that are made up of 11 projects and services to families with children in Rhode Island, including families of children with special needs. The four program areas include Parent Consultant Programs, Family Voices, Parent Information and Resource Center (PIRC) and the Parent Training and Information Center (PTIC).

Vivian Weisman  
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- <sup>6</sup> Osher, T., et. al. (1998). *New Roles for Families in Systems of Care*, Vol. 1. Systems of Care Promising Practices in Children’s Mental Health. Washington, DC: U.S. Department of Health and Human Services and Alexandria, VA: The Federation of Families for Children’s Mental Health.
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