



NewsLine

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The Federation for Children with Special Needs

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Summer Solstice Event a Huge Success

On June 21st, 2002, at Anthony's Pier 4 in Boston, Parents for Residential Reform (PFRR) and the Federation for Children with Special Needs, in collaboration with Mass Families Organizing for Change, held the Summer Solstice Dinner Dance and Silent Auction to benefit the Children's Holiday Gift Fund.* The PFRR board and other volunteers worked hard to make this event successful and fun.

The Master of Ceremonies was our own Dan Heffernan, Esq., Chairman of Federation's Board of Directors. Dan stepped in for OLDIES 103.3 Paula Street who was ill and

he did a fantastic job! Cassandra Watson-Colon, one of the people who helped create the Children's Holiday Gift Fund, spoke eloquently about the children and adolescents living with disabilities that were without gifts and sometimes even without family and friends during the holiday

season. Sharing her own remembrances of her residential school days, Cassandra spoke about how truly alone these children are. After the holidays, she and her friends would return to



L to R: Federation Executive Director Rich Robison, Andrea Watson of PFRR, Senator John Kerry (MA), Susan Nadworny of Massachusetts Families Organizing for Change, and Commissioner Harry Spence, DSS.

school with gifts, and laugh and talk about their good times with family and friends, and realized the children who remained at school

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ICC Parent Leadership Development Project Underway

The Federation is pleased to share with you the exciting news that our proposed National ICC Parent Leadership Development Project has been funded by the U.S. Department of Education for three years beginning October 1, 2002. The planning process for the new grant has already begun. We are examining the current needs of parents serving on state ICC's as well as using the suggestions of previous participants including the lessons learned from the last three Parent Leadership Institutes to plan our future activities.

Barbara Popper and Rich Robison will serve as Co-project Directors; Marilyn Gutierrez and Brad Arndt will staff the project. Roberto Chene, from New Mexico, Cassie Johnston of Washington State, and Kathleen Osta from Texas will continue to function as our Institute faculty. Joseph Telfair of the University of Alabama will be our project evaluator.

Together we will provide training opportunities to five state teams per year, support state team building and assist teams in identifying collaboration activities with key organizations

within and between states. State teams will establish their own models of training activities to be replicated at their state level, and develop reciprocal outreach strategies to reach diverse and underserved parent populations.

The listserv we have managed for parents (iccparent) is being re-activated. Our ICC Parent website (www.iccparent.org) is being redesigned and updated. Brad Arndt at the Federation will manage these activities and welcome new parents who join the list.

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The cost of mailing *NewsLine* continues to climb. If you would like to receive *e-NewsLine*, just go to fcsn.org and click on "*NewsLine*."

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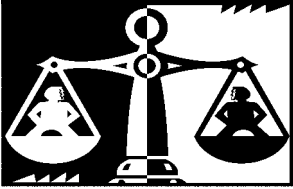


Bulletin

Parents Learning About Children's Education



Legislative & Policy Update



No Child Left Behind: A New Law for All Students

The *No Child Left Behind Act* was signed into law on January 8, 2002. This law changes the role of the federal government in kindergarten through 12th grade educational programs.

On July 19, Dr. Susan Scalfani, Counselor to Secretary Rod Paige of the United States Department of Education, visited the Federation and presented an overview of the requirements of the recently passed *No Child Left Behind (NCLB) Act*. Representatives from the Massachusetts Department of Education, Massachusetts Department of Public Health, the Perkins School, the Shriver Center and others joined Federation staff members to discuss the latest developments in education reform.

The four key principles of the Act are:

1) Accountability. Each school is now held accountable for the quality of education they provide for their students. Schools must measure levels of performance/improvement for all groups of students through annual assessments beginning in 3rd grade, through grade 8, and at least once in high school. States must establish a definition of adequate yearly progress (AYP) for the schools in their state. If a school doesn't make adequate progress for a period of two years, they will be identified as "a school in need of improvement."

At this point the school district itself must address the issue. If a school still doesn't progress, more drastic measures must be taken by the state. When a school is at "needs improvement" status, the district must reserve 20% of its federal funds (for example, Title 1 funds) to be used for supplemental services and school improvement activities.

2) Flexibility and local control. Local school districts have flexibility to reallocate federal resources to meet the needs that are most important to their success. For example, class size reduction funds could be redirected to a block grant for teacher quality. The new regulations are more flexible and allow states and individual school districts to address local needs and regional differences. Also there will be more flexibility to move money from other Titles of the Act to address the areas of greatest need. These should be state and locally driven decisions.

3) Parental choice. NCLB views parents as equal partners in the educational process and expands options for parents who want their children to attend a good school and receive a quality education. Research has shown that if a child has three low-performing teachers in a row, the student will achieve at significantly lower performance levels. Under NCLB,

parents have a unique opportunity and responsibility to work in partnership with their children's schools to ensure all students are achieving academically and that the school is making adequate progress. Parent participation is defined in the law as "participation in regular, two-way and meaningful communication involving student academic learning and other school activities..." NCLB gives parents the choice to move their student to a different (publicly funded) school within the district if the child's own school remains in low performing status for more than three years. Parents of children with disabilities would also be able to exercise this choice if their child is in a low-performing school. When parents change their child's placement, the funds follow the child to the new school.

4) Research-based practice. Good educational practice must be upheld by the results of sound research. There is a widely recognized need for more research about education. Therefore, an aggressive research agenda is being promoted for literacy, reading instruction, math and effective teaching, among other topics. Pre-service training and professional development activities for professional staff are being looked at carefully. Also, alternative pathways to teacher certification are emerging across the country.

Students with disabilities are protected under NCLB. It is important to recognize that "all means all" including students with special needs. The legislation requires testing of all children to determine student achievement and adequate yearly progress for schools. The test results must report overall school progress as well as be reported in several sub-categories such as ethnic/racial category, economic disadvantage, English as a second language, and disability.

The law includes a "Safe Harbor" provision, which recognizes that not every group of students will meet the definition of adequate progress. The Safe Harbor provision allows for schools to show progress by reducing the number of failing students within particular categories by 10% per year. The law also anticipates that there are some students who may be difficult to test, such as students with cognitive disabilities, and that the safe harbor provisions will help schools with this group. Finally, the law requires the reporting of scores for sub-groups of students only for statistically significant groups of students. The group size will likely be 30-50 students.



SAVE THE DATE!



Gala 2003

Celebrate with the Federation for
Children with Special Needs

Friday, May 9th, 2003 at 6 pm
Royal Sonesta Hotel, Cambridge, MA

From the Executive Director

State-Endorsed Certificates: A transition pathway or a two-tiered system?

My wife and I are now officially “transition” parents. Last June, we proudly watched our daughter Amy march with her class at their commencement ceremony. However, rather than receiving a diploma, Amy was presented with a certificate from her school. It is important to note that she participated in commencement with her peers, but has not yet “graduated” from high school. This ensures that her services under IDEA continue as she makes her transition to adult living. Presently she is attending a course at a community college, has two supported employment settings and is working out four days a week. She has an active and appropriate program for her needs, but not all of it came easily.

I’ve talked with other parents who have told me that their child with similar issues has been refused transition services by the school district or offered too little to be satisfactory. This is not surprising, as one of the key findings of the U.S. DOE’s Office of Special Education Programs (OSEP) was that transition services were not fully implemented in Massachusetts (or many other states). It seems there are few clear paths for how to implement transition services that will assist students with significant disabilities in establishing appropriate post secondary education or meaningful employment for themselves. This is not a new dilemma.

Recently, the Massachusetts Board of Education, based upon a recommendation from the Commissioner of Education David Driscoll, has proposed to establish a state endorsed Certificate of Achievement for students who meet all local graduation requirements, but have not yet met the MCAS competency determination. The intention is to recognize the achievements of students who have done everything possible to pass MCAS, and to provide pathways for their continued achievement, without lowering the competency standard.

For students with disabilities, this could be an important development and this is why. Under IDEA-97, a student’s educational entitlement ceases when they graduate with either a “state

standard diploma” or after their 22nd birthday, whichever comes first. Historically, local school districts had sole authority to grant diplomas and all too frequently did so for students with disabilities who had met their IEP goals, but were not yet ready to graduate and still needed transition services. For example, a student with Asperger’s syndrome received a diploma from his local high school at age 19,

Historically, local school districts had sole authority to grant diplomas and all too frequently did so for students with disabilities who had met their IEP goals, but were not yet ready to graduate and still needed transition services.

and in so doing he forfeited his right to receive educational services for the next three years, though he clearly needed transition supports. He needed job-skills training, continued academic support, and support navigating his community safely. Because he “graduated,” the school no longer had any responsibility. At the same time the adult services systems and state agencies did not find him qualified for their services or indicated there was no money available to fund services. The result was that he was stuck at home, watched too much TV and became extremely depressed. His mother had to quit her job and became his primary social and community support and care giver.

The intention of IDEA and Education Reform is that all students achieve to their highest ability and become independent adults and full participants in their communities. The MCAS requirement has made it absolutely clear and illegal for schools to prematurely “graduate” any student before age 22. Under the current proposal, a student who is not able to pass MCAS could receive a state-endorsed certificate, which would be recognized by community colleges and job training programs



Richard Robison

for continued training and support. Clearly, the sending school district would have the primary responsibility under IDEA, but this may be a way to create more appropriate opportunities for transition services and supports for students who have lost out in the past.

If the right programs will recognize and cooperate, the certificate proposal could become a real pathway for appropriate and effective transition services. If not, the certificate could just become a second-class alternative to the real thing.

Richard J. Robison

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3. Review the requirements of your matching gifts program carefully—each program has its own policies.

*You can contribute to The Federation for Children with Special Needs online!
Go to www.fcsn.org for details.*



Ask an Expert!

Empowerment Through Information

by Mary Loughlin
Federation Information Specialist

PARENT-PROFESSIONAL COLLABORATION

Dear Expert,

I remember when I took the Federation's Basic Rights Training that we talked about how parents are partners in their children's education. How exactly do I go about building parent-professional partnerships with the teachers, administrators and other staff at my child's school?

Parent without a Partner in Education

Dear Parent,

When school staff and parents work together to support each other, it also supports your child. Developing a good relationship with school staff requires mutual respect and trust, which is built over time.

Many conflicts between parents and school staff arise due to different perspectives and limited resources. The school staff must meet the needs of many students while parents have only their own children's needs in mind. When parents, who are deeply invested in their children, see unmet needs, needs perhaps unidentified and thus unmet by the schools, they are compelled to advocate strongly for what they feel their children need. School

staff, on the other hand, are often trying very hard to help a great many children with limited resources and limited information about an individual child's needs. Parents and schools can resolve and/or avoid conflicts by gathering more information about the situation and by developing a partnership.

The best way to develop parent-professional partnerships is to communicate with your child's school as often as possible through phone calls, written notes, parent-teacher conferences, and team meetings. Keep communications positive and caring. Monitor your child's progress, respond to problems and ask your child's teachers about changes you can implement at home to support your child's learning.

Parents can build partnerships with the school and other families by becoming actively involved in other aspects of school life. Read the school handbook and learn about school policies and programs. Become informed about school district and state policies so you can have input into those policies that affect your child's education. Join the Parent Teacher Association or Organization (PTA or PTO) and Special Education Parent Advisory Council (PAC) so you can connect with other

families and share experiences and resources for your child and your school. Read the communications from school: surveys, newsletters, calendars, flyers, and you will learn about even more opportunities where your participation will be welcomed.

Most schools have volunteer programs. By volunteering, you can: become more comfortable and feel like part of the school community, understand the teacher's job, and learn activities to carryover at home. Through learning activities with your child at home, you can support, encourage, and help your child.

Over 35 years of research recognizes that when families of children become involved in their children's education, there are significant effects on children's achievement and positive benefits for schools. In other words, parent-professional collaboration is a win-win-win situation for your child, your school, and you! That collaboration is only possible, however, when all partners welcome, understand, accept, respect, and trust each other enough to communicate openly and honestly in positive, caring terms.

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Tribute to Beverly (Harte) Graham, 1924-2002

We were saddened to learn of the death of Beverly Graham on June 11, 2002. Beverly was one of the co-founders of the Federation and she had represented children with mental retardation on the coalition that lobbied for enactment of Chapter 766.

Always a strong advocate for children with retardation, and later for children with all disabilities, Beverly brought extensive knowledge and deep sensitivity to her work with parents at the Federation. She headed the first project to implement the legal requirement for surrogate parents.

Beverly and her husband Bill were among the pioneer parents who flatly refused to place their disabled children in an institution and instead they worked tirelessly for their daughter's equal education rights and inclusion in her home community.

The many devoted friends and colleagues at the Federation will sorely miss Beverly's inspiration and her contagious sense of humor. Her Federation friends will especially miss Beverly's generous hospitality at the Graham house by the ocean in Seabrook, New Hampshire. For many years, those annual weekends brought personal refreshment and renewed energy for the hard work performed by the Federation staff.

—Martha Ziegler and Betsy Anderson

***“And I will not change the last word of the story.
It is still love.”***

—Clare Claiborne Park

Summer Solstice Event

continued from page 1

had no one with whom to celebrate the holidays. She did a wonderful job expressing the need for funds to help provide age appropriate gifts during the holiday season for these young people, and explained how a holiday gift could make such a difference in their lives, and give them much-needed feelings of self worth to be able to go on and be successful.

Recipients of this year's Powerful Friends Awards were the Honorable U.S. Senator John Kerry, who gladly accepted this award himself; Richard Sheola, President of Public Sector at Value Options; and Attorney Tim Sindelar of the Disability Law Center. Tim was also honored with the Leadership Award from MASSPAC that evening.

One of the highlights of our Summer Solstice Event was the generous and wonderful \$2000 donation presented by two representatives for singer Johnny Rivers and his fan club to the fund. Now that was a Mountain of Love!

As they have for the last four years, our friends, the Marsels, provided the entertainment and had almost everyone on the dance floor until well after midnight. Our thanks to



Senator Kerry and Cassandra Watson-Colon all who volunteered, donated, and attended. We hope to see you again next year.

If you would like to make a donation to the Children's Holiday Gift Fund, please send a check to the Federation for Children with Special Needs at 1135 Tremont Street—Suite 420, Boston, MA 02120. Checks should be made out to FCSN-CHGF.

** The Children's Holiday Gift Fund benefits children and adolescents with disabilities who have little or no family involvement, are in state custody, and who reside in residential/group home care. The fund helps purchase age appropriate gifts for these children during the holiday season.*

NewsLine

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The Federation for Children with Special Needs, Inc.

Our Mission:

To provide information, support, and assistance to parents of children with disabilities, their professional partners, and their communities. We are committed to listening to and learning from families, and encouraging full participation in community life by all people, especially those with disabilities.

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Health Care: Understanding Options, Making Choices

by Dotty Robison
Heller School for Social Policy and Management
Brandeis University

As the mother of three children, two of whom have Down syndrome and a variety of special health care needs, I know that information about health care is crucial. I am also Research Associate at the Heller School at Brandeis University. This essay is based on a recently published article, "Navigating Systems of Care: Results From a National Survey of Children with Special Health Care Needs." The survey, which collected data from 2200 parents of children with special health care needs, provides useful information for parents who are navigating health care systems. The survey was the result of a joint effort between researchers at the Heller School, Brandeis University, Waltham, MA, and Family Voices, a national grassroots advocacy organization based in Albuquerque, NM, that works to benefit children with special health needs and their families. Parents are the experts about the health care their children need and are an important source of information for each other. The authors of the survey wanted to find out about parents' experiences as they work their way through the maze of health care services for their children. Results from this survey may be useful to parents in their efforts to obtain medical care for their children.

THE STUDY'S METHODS:

In each of 20 states, including Massachusetts, parents were recruited through the Family Voices mailing list and from the list of families who participate in the state Title V Children with Special Health Care Needs program. The survey was available in both English and Spanish, and was mailed to over 6,000 parents in 1998 and 1999. Over 2,000 surveys were completed and returned.

THE STUDY PARTICIPANTS AND THEIR CHILDREN WITH SPECIAL HEALTH CARE NEEDS:

In a majority of cases, the person who completed the survey was the mother of the child with special health care needs. To qualify for the study, the child had to be under 18 years of age, live at home, and have a health condition expected to last for at least one year. Over one-fourth were of a minority background.

Almost half of the children were reported to be in either excellent or very good health, over one-third had a health condition, which was rated as severe, and one-fourth had health conditions which were changing all the time.

THE STUDY'S FINDINGS:

The study yielded four primary findings:

- Most children received health insurance coverage and related services from multiple

"We, as parents, do most of the coordination because we are, unfortunately, more knowledgeable. The frequent turnover of staff and overworked and untrained staff necessitates this. We have had four case managers in the past 3 years."

sources. Also, almost half of the children had both a primary and a secondary health plan. Children received services from early intervention programs, school systems, or the state's Department of Mental Retardation or Developmental Disabilities. Slightly less than half of the children received speech, occupational, or physical therapy, the cost of which was usually covered by the child's school system. More than a quarter of the children received home health services and less than one fifth received mental health services. Ninety-seven percent of the children were enrolled in a health care plan. A total of 40% of the children were reported to have a secondary health plan in addition to their primary plan, and of these children, 86% of the participants reported that the secondary plan was publicly financed. A majority of children received services from specialty doctors and used prescription med-

ications. Services were covered mostly by health plans or by another public program. Families also paid at least a portion of the expenses for services.

- Receiving coverage and services from a variety of sources makes advocating for children's needs more complicated. Often, parents must work their way through the regulations of health plans, government agencies, and their child's educational system. Parents reported problems with getting referrals and appointments, finding skilled providers, getting authorization for the number of visits needed, coordination of services among providers, and the money parents had to pay for services.

- One-half of the parents reported that their child has a case manager to help obtain services. A publicly funded program usually provided the case manager. In a few cases, the case manager was provided by the health plan. Most parents whose child had a case manager said he/she had a good knowledge of their child's needs. Parents were asked to share their experiences in their own words. One parent said, "Our case manager is wonderful. She provides parent network information, whole family support, and flexible funding. She attends IEP meetings as the advocate and advocates for insurance coverage."

Other parents reported that they don't always receive adequate information about how to get services for their child and that the services received from the case manager are not always what they need. One parent shared these thoughts: "We, as parents, do most of the coordination because we are, unfortunately, more knowledgeable. The frequent turnover of staff and overworked and untrained staff necessitates this. We have had four case managers in the past 3 years."

- Most parents said they were satisfied with their child's primary health plan. Three-quarters would recommend their child's primary health plan to other families, and over two-thirds said they would probably not change their primary health plan if they had that option.

On the other hand, parents were less satisfied with the amount of information health plans provided about needed services. Parents also expressed a need for greater access to skilled specialists, even if the specialist was outside their health plan's network.

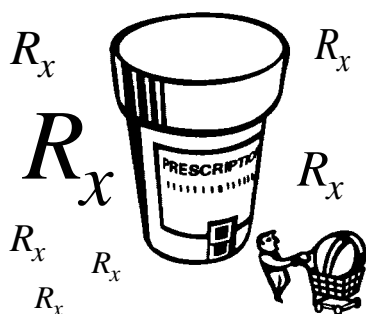
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Parents were asked what advice they would give to other families when choosing a health plan for their child with special health care needs. One parent wrote, "Be careful. Read even the fine print. Find someone you trust. Ask lots of questions. There are good plans that have caring, competent doctors who will work for you and with you. Only learn to trust your own judgment. It's your child. No one knows them better."

ADDITIONAL SUGGESTIONS FOR PARENTS:

In thinking about the findings from this study, I thought about what parents might do to better manage the coordination of their child's care. I would like to make the following suggestions:

- **Take a look at your child's health plan with his or special health care needs in mind.** Although your child's health may be stable at the present time, it is helpful to know what services are available and what coverage is provided before a health crisis occurs. Contacting your employer's Human Resources department is a good place to start. Information important to consumers choosing health plans is also available on the web at www.ahcpr.gov/consumer.
- **Consider applying for a secondary health plan for your child.** Many children with special health care needs are eligible for a secondary health plan, which supplements services provided by the primary health plan. Eligibility is sometimes based on income, but is often based on disability or need. Your child may also be eligible for care coordination services. Contact MassHealth, our

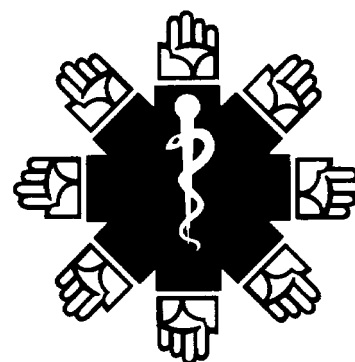


state's Medicaid program, at www.state.ma.us/dma/ or call 1 800-841-2900 to find out if your child may be eligible for the CommonHealth program. CommonHealth is one of the types of MassHealth available to middle income families who pay a sliding scale fee based on income for supplemental health insurance coverage for their child.

- **Contact parent organizations to learn about your child's rights and about programs and services in your state.** Family Voices www.familyvoices.org has helpful information on many aspects of health care for children with special health care needs. The telephone number is 1-888-835-5669. You may also contact the Massachusetts chapter of Family Voices at www.massfamilyvoices.org or by calling the Federation at 1-800-331-0688.
- **Find out about the resources that are available to help you coordinate your child's health care.** You may contact the National Center of Medical Home Initiatives for Children with Special Needs at www.medicalhomeinfo.org. The National Center works with federal agencies, doctors, other professionals, and families to overcome barriers to health care supports and services that often arise for children with special health care needs. Contact Massachusetts Family TIES www.massfamilyties.org to find out more about medical home in Massachusetts or care coordination services.

ACKNOWLEDGEMENT:

The research discussed in this article is: Krauss, M, Wells, N., Gulley, S., Anderson, B. (2001). Navigating Systems of Care: Results



From a National Survey of Families of Children With Special Health Care Needs. *Children's Services: Policy, Research, and Practice*, 4, 165-87.

The research projects that provide the foundation for this and future essays are conducted by *The Consortium for Children and Youth with Disabilities and Special Health Care Needs*, a partnership of Georgetown University's Center for Child and Human Development, The Heller School at Brandeis University, the Institute for Child Health Policy (University of Florida), and Family Voices. *The Consortium* is funded by N.I.D.R.R. of the U. S. Department of Education.

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Cuidados de la salud: Entendiendo las opciones y tomando decisiones

*Dotty Robison
Heller School para la política social y de gobierno
Brandeis University*

Como madre de tres niños, dos de los cuales tienen el síndrome de Down y una variedad de necesidades de cuidados de salud, estoy segura de que la información acerca de los cuidados de la salud es de suma importancia. También soy investigadora asociada en la Heller School en Brandeis University. Este escrito está basado en un artículo publicado recientemente "Navigating Systems of Care: Results from a National Survey of Children with Special Health Care Needs." La encuesta, la cual contiene información proporcionada por 2.200 padres de familia de niños con necesidades de cuidados de salud especial, ofrece información importante para padres de familia que están en este momento inmersos en los sistemas de salud. La encuesta fue el resultado del esfuerzo común entre investigadores en la Heller School de Brandeis University en Waltham, Massachusetts y Family Voices, una organización nacional de defensa de las familias ubicada en Albuquerque, New Mexico. Esta organización trabaja en beneficio de niños con necesidades de cuidados de salud especial y sus familias. Los padres de familia son los expertos acerca de los cuidados de salud que necesitan sus hijos y a la vez se convierten en una fuente importante de información entre ellos. Los que realizaron las encuestas querían encontrar cuales fueron las experiencias de los padres de familia durante todo el curso del proceso de obtener servicios de salud para sus hijos. Los resultados de esta encuesta pueden ser de gran ayuda para otros padres de familia en sus esfuerzos por obtener cuidado médico para sus hijos.

LOS MÉTODOS DEL ESTUDIO:

En cada uno de los 20 estados, incluyendo Massachusetts, los padres de familia fueron seleccionados por medio de las listas de Family Voices y también por las listas de las familias que participaron en el programa estatal Título V de niños con necesidades de cuidado de salud especial. La encuesta estuvo al alcance de los padres de familia en ambos idiomas inglés y español y fue enviada por correo a más de 6.000 padres de familia en 1998 y 1999. Mas de 2,000 encuestas fueron devueltas.

LOS PARTICIPANTES DEL ESTUDIO Y SUS NIÑOS CON NECESIDADES DE CUIDADOS DE SALUD ESPECIAL.

En la mayoría de los casos la persona que lleno la encuesta fue la madre de un niño o niña con necesidad de cuidado de salud especial. Para ser parte de este estudio el niño tenía que cumplir

"Nosotros, como padres, tenemos la mayoría de la coordinación de servicios, porque desafortunadamente, tenemos más conocimiento que la trabajadora social. Esto se debe a que hay un continuo cambio de personal que esta sobre cargado de trabajo y con falta de entrenamiento y por lo tanto no pueden atender nuestras necesidades."

con los siguientes requisitos: menor de 18 años, vivir en la casa de sus padres y tener una condición de salud que se espera que dure por lo menos un año. Mas de un cuarto de los participantes fueron minorías. Se reporto que cerca de la mitad de los niños estaban con muy buena o excelente salud. Mas de la tercera parte tenían una condición de salud, que fue establecida como severa, y un cuarto de ellos tenían condiciones de salud que cambiaba en todo momento.

RESULTADOS DEL ESTUDIO:

Hubo cuatro descubrimientos importantes:

- **La mayoría de los niños recibe seguro de salud y servicios relacionados de diferentes fuentes. A la misma vez se encontró que cerca de la mitad de los niños tienen planes de salud primarios y secundarios.** Los niños reciben servicios de programas de intervención temprana, de sistemas escolares, o del departamento de retardacion mental, o de

desarrollo de discapacidades. Un poco menos de la mitad de los niños reciben terapia del lenguaje, ocupacional o física y el costo de la misma fue casi siempre cubierto por el sistema escolar del niño. Mas de un cuarto de los niños reciben servicios de salud en la casa y menos de una quinta parte reciben servicios de salud mental. El noventa y siete por ciento de los niños estaban inscritos en un plan de salud. Un total de 40 % de los niños reportaron tener un segundo plan de salud y el 86 % de estos niños reportaron que este segundo plan era financiado con dinero público. La mayoría de los niños recibieron servicios de doctores especialistas y recibieron medicinas recetadas. Los servicios médicos fueron pagados por seguros de salud o por un programa de salud público. Las familias también pagaron una porción de los gastos por estos servicios.

- **Recibir seguro de salud y servicios de diferentes fuentes hace más complicado interceder por las necesidades de los niños.** Con frecuencia los padres de familia tienen que encontrar la forma de cumplir con los requisitos de los planes de seguro, de agencias estatales y del sistema educativo de su niño. Los padres de familia reportaron que tenían problemas para: encontrar citas, ser referidos, encontrar especialistas, conseguir autorizaciones para el número de visitas necesarias, coordinar los servicios entre los proveedores y con la cantidad de dinero que los padres tenían que pagar por dichos servicios.
- **La mitad de los padres de familia reportaron que sus hijos tiene una trabajadora social que les ayuda a obtener los servicios.** Un programa que recibe fondos públicos usualmente provee una trabajadora social. En algunos casos, la trabajadora social es proporcionada por el plan de salud. La mayoría de los padres que tuvieron los servicios de la trabajadora social dijeron que el o ella tenía un buen conocimiento de las necesidades de sus hijos. Se les pidió a los padres de familia que compartieran sus experiencias. Un padre de familia dijo: "*Nuestra trabajadora social es maravillosa. Ella nos ha dado información para comunicarnos con otros padres, nos proporciona apoyo familiar y es flexible en la manera de usar los fondos. Ella asiste a las reuniones de equipo en la escuela como nuestra defensora e intercede para conseguir un buen seguro de salud.*"

Otros padres reportaron que no siempre reciben información adecuada acerca de como obtener los servicios para sus niños y

que los servicios de la trabajadora social no son siempre lo que ellos necesitan. Un padre nos comparte este pensamiento: *“Nosotros, como padres, tenemos la mayoría de la coordinación de servicios, porque desafortunadamente, tenemos más conocimiento que la trabajadora social. Esto se debe a que hay un continuo cambio de personal que esta sobre cargado de trabajo y con falta de entrenamiento y por lo tanto no pueden atender nuestras necesidades. Nosotros hemos tenido 4 trabajadores sociales en los últimos 3 años.”*

- **La mayoría de los padres dijeron que estaban satisfechos con el plan de salud primario de su hijo.** Tres cuartos recomendarían el mismo plan de salud primario de sus hijos a otras familias y más de dos tercios de ellos dijeron que si tuvieran la opción de cambiar, ellos probablemente no cambiarían su plan de salud primario.

De todas maneras, los padres de familia estaban insatisfechos con la cantidad de información que los planes de salud proporcionan acerca de los servicios. Los padres de familia también expresaron que existe una gran necesidad de un mayor acceso a especialistas, aunque estos no estén asociados con el plan de salud.



Se les preguntó a los padres de familia que cual sería el consejo que ellos darían a otras familias cuando ellas estén eligiendo el plan de salud para sus niños con necesidades especiales de cuidado de salud. Un padre escribió: *“Tengan cuidado. Lean hasta la letra pequeña. Busquen a alguien en quien confiar. Hagan todas las preguntas necesarias. Existen buenos planes que tienen doctores competentes que trabajaran por ustedes y con ustedes. Solamente aprendan a creer en su propio juicio. Son sus hijos y nadie los conoce mejor que ustedes.”*

SUGERENCIAS ADICIONALES PARA LOS PADRES DE FAMILIA.

Pensando en el resultado de este estudio. Quisiera hacer algunas sugerencias para que los padres de familia puedan administrar y coordinar mejor el cuidado de su hijo:

- **Revise el plan de salud de su hijo teniendo en mente sus necesidades especiales de salud.** A pesar de que la salud de su hijo este estable en este momento, es importante saber que servicios están disponibles y si su hijo esta cubierto antes de que una crisis de salud ocurra. La oficina de recursos humanos de su lugar de trabajo es el mejor lugar para empezar a investigar. Información para los consumidores que están buscando un plan de salud esta disponible en el web www.ahcpr.gov/consumer

- **Piense en la posibilidad de aplicar para un segundo plan de salud para su hijo.** Muchos niños con necesidades especiales de salud pueden aplicar por un segundo plan de salud, el cual puede proveer servicios adicionales que complementen el plan de salud primario. La elegibilidad esta basada en el ingreso de la familia, pero algunas veces esta basado en la discapacidad o necesidad. Su hijo puede ser elegible para servicios de coordinación de cuidado. Llame a MassHealth, el programa de Medicaid del estado al 1800-841-2900 o en el web www.state.ma.us/dma para averiguar si su hijo puede aplicar para el CommonHealth program. CommonHealth es un de los tipos de MassHealth disponible a familias de medianos ingresos quienes pagan una cantidad reducida para cubrir los servicios adicionales de salud que sus hijos necesitan.

- **Llame a organizaciones de padres de familia para aprender más acerca de los derechos de su hijo y de los programas y servicios que existen en el estado.** Family Voices, www.familyvoices.org, tiene información sobre muchos aspectos de salud para niños con necesidades especiales de cuidados de salud. El número de teléfono es 1-888-835-5669. También puede llamar a la oficina de Family Voices en Massachusetts en la Federación al 1-800-331-0688 o su web www.massfamilyvoices.org

- **Averigüe los recursos disponibles que le puedan ayudarle a usted a coordinar los cuidados de salud de su hijo.** Usted puede comunicarse con el National Center of Medical Home Initiatives for Children with Special Needs en www.medicalhomeinf.org. El National Center trabaja en coordinación



con varias agencias federales, doctores, otros profesionales y familias para vencer los obstáculos que muy frecuentemente existen con niños con necesidades especiales de salud cuando estos necesitan apoyo y servicios. Puede comunicarse también en Massachusetts con Family TIES www.massfamilyties.org para encontrar más información acerca de “medical home” en el estado o sobre los servicios de coordinación de cuidados de la salud.

RECONOCIMIENTOS.

La investigación discutida en este artículo es: Krauss, M, Wells, N., Gulley, S., Anderson, B. (2001). “Navigating System of Care: Results from a National Survey of Families of Children with Special Health Care Needs. *Children’s Services: Policy, Research, and Practice*, 4, 165-87.

The research projects that provide the foundation for this and future essays are conducted by *The Consortium for Children and Youth with Disabilities and Special Health Care Needs*, a partnership of Georgetown University’s Center for Child and Human Development, The Heller School at Brandeis University, the Institute for Child Health Policy (University of Florida), and Family Voices. *The Consortium* is funded by N.I.D.R.R. of U.S. Department of Education.

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Assistência de Saúde: Compreendendo as Opções, Fazendo Escolhas

*Doty Robison
Heller School para la política social y de gobierno
Brandeis University*

Como mãe de três filhos, dois deles com Síndrome de Down e com várias necessidades especiais de cuidados médicos, eu sei que as informações sobre assistência de saúde são cruciais. Sou, também, Pesquisadora Associada da Heller School, na Brandeis University. Este ensaio é baseado num artigo publicado recentemente, "Navigating Systems of Care: Results From a National Survey of Children with Special Health Care Needs" (Navegação dos Sistemas da Saúde: Resultados de uma Pesquisa Nacional sobre Crianças com Necessidades Especiais de Assistência de Saúde). A pesquisa de opinião, que coletou dados de 2200 pais de crianças com necessidades especiais de assistência de saúde, fornece informações úteis aos pais que 'navegam' pelos sistemas de assistência de saúde. A pesquisa foi o resultado de um esforço conjunto entre os pesquisadores da Heller School, Brandeis University, Waltham, MA, e da Family Voices, uma organização sediada em Albuquerque, NM. Que trabalha em benefício de crianças com necessidades especiais e as suas famílias. Os pais são os especialistas sobre a assistência de saúde que seus filhos precisam e constituem uma fonte importante de informações entre si. Os autores da pesquisa queriam saber a respeito das experiências dos pais quando estes se defrontam com o labirinto dos serviços de saúde para seus filhos. Os resultados deste levantamento podem ser bem úteis, para os pais, em seus esforços para obter assistência médica para seus filhos.

OS MÉTODOS DO ESTUDO:

Em cada um dos 20 estados, incluindo Massachusetts, os pais foram selecionados através da lista da mala-direta da Family Voices e, também, da lista de famílias que participaram do programa para Crianças com Necessidades Especiais de Assistência de Saúde do artigo de lei "Title V". A pesquisa estava disponível em inglês e espanhol, tendo sido remetida pelo correio para mais de 6.000 pais em 1998 e 1999. Mais de 2000 questionários foram preenchidos e enviados de volta.

OS PARTICIPANTES DO ESTUDO E SUAS CRIANÇAS COM NECESSIDADES ESPECIAIS DE ASSISTÊNCIA DE SAÚDE:

Na maioria dos casos, quem completou o questionário foi a mãe da criança com necessidades especiais de assistência de saúde. Para qualificar-se para o estudo, a criança teria

Nós, como pais, fazemos a maior parte da coordenação, pois temos, desafortunadamente, mais conhecimentos. A troca freqüente de pessoal, e os funcionários sobrecarregados e distreinados resultam nisso.

de ser menor de 18 anos de idade, morar em casa e ter uma condição médica esperada para durar por pelo menos um ano. Mais de um quarto era de base minoritária. Quase a metade das crianças foram relatadas como estando com uma saúde excelente ou muito boa; mais de um terço tinha uma condição médica classificada como severa; e um quarto tinha condições médicas que variavam o tempo todo.

AS DESCOBERTAS DO ESTUDO:

O estudo rendeu quatro descobertas primárias:

- **A maioria das crianças recebe cobertura de seguro de saúde e de serviços relacionados de múltiplas fontes. E, quase a metade das crianças tem ambos, planos primário e secundário de seguros de saúde.** As crianças recebem serviços de programas de intervenção preventiva, do sistema escolar, ou do Departamento de Retardamento Mental ou de Desenvolvimento de Deficiências. Um pouco menos da metade das crianças recebia fonoaudiologia, terapia ocupacional ou fisioterapia, sendo os custos geralmente cobertos pelo sistema escolar das crianças.

Mais de um quarto das crianças recebia serviços de saúde em casa e menos que um quinto recebia serviços de saúde mental. 97% das crianças tinha um plano de seguro de saúde. Foi constatado que um total de 40% das crianças tinha um plano de saúde secundário em adição ao plano primário, e, destas crianças, 86% dos participantes relataram que o plano secundário tinha financiamento público. A maioria das crianças recebia serviços de um médico especializado e usava medicamentos com receita. Os serviços eram cobertos, em sua maior parte, pelos planos de saúde ou por um outro programa público. As famílias também pagavam ao menos uma parte das despesas pelos serviços.

- **O recebimento de coberturas e serviços de fontes variadas torna a defesa das necessidades das crianças mais complicado.** Frequentemente, é necessário que os pais se defrontem com os regulamentos dos planos de saúde, agências governamentais e o sistema escolar dos filhos. Os pais declararam que tinham problemas em obter recomendações e marcar apontamentos, encontrar provedores de serviços com qualidade, obter autorização para o número de visitas necessárias, com a coordenação de serviços entre os provedores e, também, com o dinheiro que eles têm de pagar pelos serviços.
- **A metade dos pais reportou que sua criança tem um gerente de caso para obter serviços.** O gerente de caso era providenciado, geralmente, por um programa com fundos públicos. Em poucos casos, o gerente de caso era providenciado pelo plano de saúde. A maioria dos pais em que o filho tinha um gerente de caso dizia que tinha um bom conhecimento das necessidades da criança. Os pais foram solicitados a partilhar suas experiências com suas próprias palavras. Uma mãe disse, "Nossa gerente de caso é maravilhosa. Ela fornece informações de rede de pais, apoio familiar integral, e financiamentos flexíveis. Ela participa das reuniões do IEP como defensora e faz a defesa pela cobertura do seguro."

Outros pais declararam que nem sempre recebem informações adequadas de como obter serviços para seus filhos, e que os serviços fornecidos pelo gerente de caso nem sempre é o que eles precisavam. Um dos pais partilhou este pensamento: "Nós, como pais, fazemos a maior parte da coordenação, pois temos, desafortunadamente, mais conhecimentos. A troca freqüente de pessoal,

e os funcionários sobrecarregados e distreinados resultam nisso. Já tivemos quatro gerentes de caso nos últimos três anos.”

- **Em sua maioria, os pais dizem que estavam satisfeitos com o plano de saúde primário de seu filho.** Três quartos recomendaria o plano de saúde primário de sua criança para outras famílias, e mais de dois terços informaram que, provavelmente, não trocariam seu plano de saúde primário se tivessem esta opção.

Por outro lado, os pais estavam menos satisfeitos com a quantidade de informações que os planos de saúde forneciam sobre os serviços necessitados. Eles também expressaram uma necessidade de um acesso maior a especialistas treinados, ainda que o especialista estivesse fora da rede do seu plano de saúde.

Foi solicitado aos pais que tipo de conselho eles dariam a outras famílias sobre a escolha de um plano de saúde para seus filhos com necessidades especiais de assistência de saúde. Uma mãe escreveu: *“Tenha cuidado. Leia até mesmo as letras pequenas. Procure alguém de sua confiança. Faça um monte de perguntas. Há bons planos com médicos competentes que trabalhariam com carinho para você, com você. Só aprenda a confiar em seu próprio discernimento. É a sua criança. Ninguém a conhece melhor.”*

MAIS SUGESTÕES PARA OS PAIS:

Pensando nas descobertas deste estudo, estive pensando no que os pais poderiam fazer para gerenciar melhor a coordenação da saúde de suas crianças. Eu gostaria de fazer as seguintes sugestões:

- **Dê uma olhada no plano de saúde de seu filho tendo em mente suas necessidades especiais de assistência de saúde.** Ainda que a saúde de sua criança esteja estável no presente momento, é bom saber quais são os serviços disponíveis e que tipo de cobertura é fornecida antes de que ocorra uma crise. Um bom lugar para iniciar é contactar o departamento de Recursos Humanos de sua empresa. Informações importantes aos consumidores escolhendo planos de saúde estão disponíveis na Internet: www.ahcpr.gov/consumer.
- **Considere uma aplicação para um plano de saúde secundário para a sua criança.** Muitas crianças com necessidades especiais de assistência de saúde são elegíveis a ter um plano de saúde secundário, o qual

complementa os serviços fornecidos pelo plano de saúde primário. A elegibilidade é, algumas vezes, baseada na renda, mas quase sempre tem como base a deficiência ou a necessidade. Sua criança também pode ter direito aos serviços de gerenciamento de casos. Contacte o MassHealth, o programa estadual de Medicaid (plano de saúde federal) no site www.state.ma.us/dma/ ou ligue 1 800-841-2900 para saber se ela pode ser elegível a fazer parte do programa “CommonHealth”. CommonHealth é um dos tipos de seguros de “MassHealth” disponível aos famílias da class média que pagam uma taxa baseada no salário familiar para uma cobertura suplemental de saúde para a sua criança.



- **Contacte as organizações de pais para saber sobre os direitos de sua criança, sobre os programas e serviços em seu estado.** A Family Voices, www.familyvoices.org, tem informações úteis sobre muitos aspectos de assistência médica para as crianças com necessidades especiais de assistência de saúde. O número do telefone é 1-888-835-5669. Você também pode entrar em contacto com a sede de Massachusetts da Family Voices no site www.massfamilyvoices.org, ou telefonando

para a Federação no tel. 1-800-331-0688.

- **Descubra os recursos que estão disponíveis para ajudá-la a coordenar a assistência de saúde de seu filho.** Você pode contactar o National Center of Medical Home Initiatives for Children with Special Needs no website www.medicalhomeinfo.org. O National Center trabalha com agências federais, médicos, profissionais diversos, assim como com famílias para derrubar as barreiras aos apoios e serviços da assistência de saúde que freqüentemente se levantam para crianças com necessidades especiais de assistência de saúde. Contacte a Massachusetts Family Ties, www.massfamilyties.org, para saber mais sobre “medical home” em Massachusetts, ou coordenação de serviços de saúde.

RECONHECIMENTOS:

A pesquisa em questão é de: Krauss, M, Wells, N., Gulley, S., Anderson, B. (2001). Navigating Systems of Care: Results From a National Survey of Families of Children With Special Health Care Needs. *Children's Services: Policy, Research, and Practice*, 4, 165-87.

Os projetos de pesquisa que fornecem os fundos para estes e futuros ensaios são conduzidos pelo *Consortium for Children and Youth with Disabilities and Special Health Care Needs*, uma parceria da Georgetown University's Center for Child and Human Development, a Heller School da Brandeis University, o Institute for Child Health Policy (University of Florida), e da Family Voices. O *Consortium* tem fundos da N.I.D.R.R. do Departamento de Educação dos E. U. A.

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Early Intervention Training Center Workshop Schedule for 2002- 2003

NOVEMBER 2002:

11/7/02 Building a Community, Part 1—
UMASS Medical Center, Worcester

11/20/02 Supporting Children's Play—
Fairfield Inn, Middleboro

DECEMBER 2002:

12/3/02 Building a Community, Part 2—
Dimock Community Center, Roxbury

12/18/02 Assessment: Taking a Close
Look—*Merrimack College, N. Andover*

JANUARY 2003:

1/8/03 Building a Community, Part 1—
Fairfield Inn, Middleboro

1/15/03 Building a Community, Part 2—
Merrimack College, N. Andover

1/23/03 Family-Centered Services:
Supporting Families in the Real World—
UMASS Medical Center, Worcester

FEBRUARY 2003:

2/6/03 Building a Community, Part 1—
*Western Regional Health Office,
Northampton*

2/13/03 Building a Community, Part 2—
UMASS Medical Center, Worcester

2/25/03 IFSP: Beyond the Nuts and Bolts—
Dimock Community Center, Roxbury

MARCH 2003:

3/11/03 Building a Community, Part 1—
Dimock Community Center, Roxbury

3/26/03 Service Coordination: Supporting
Families' Priorities and Needs—*Fairfield
Inn, Middleboro*

APRIL 2003:

4/10/03 Building a Community, Part 1—
Merrimack College, N. Andover

4/30/03 Building a Community, Part 2—
Fairfield Inn, Middleboro

MAY 2003:

5/15/03 Building a Community, Part 1—
UMASS Medical Center, Worcester

5/22/03 Building a Community, Part 2—
*Western Regional Health Office,
Northampton*

5/27/03 Supporting Children's Play—
Dimock Community Center, Roxbury

JUNE 2003:

6/10/03 Building a Community, Part 2—
Dimock Community Center, Roxbury

6/26/03 Assessment: Taking a Close
Look—*UMASS Medical Center, Worcester*

JULY 2003:

Building a Community, Part 2. **To Be
Determined, week of 7/14/03**—
Merrimack College, N. Andover

SEPTEMBER 2003:

Building a Community, Part 2. **To Be
Determined, week of 9/8/03**—*UMASS
Medical Center, Worcester*



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Workshops for Parents of Children in Residential Settings

Workshops are free of charge for parents and PACs.

To register or to schedule a workshop call 1-800-672-7084 or email pfrr@fcsn.org

Residential Schools— Know Your Rights:

This workshop gives an overview of the rights of consumers and their children in residential schools. Topics covered include, but are not limited to, laws, regulations, oversight, complaint processes, state agencies (their roles and responsibilities), access to the general curriculum, MCAS, custody, and much more. We will also discuss effective communication strategies when dealing with staff and others at a residential school. If appropriate, we will also cover the establishment of PAC's at 766-approved residential schools.

Residential Schools and The Maze of State Agencies:

DOE, DSS, OCCS, DMH, DMR, CHINS, and DYS—what's it all mean? This workshop gives information and insight into the different state agencies, their roles and responsibilities, cost share, and custody. It also explains community-based resources, how to find and obtain them.

Preparing for Transition from Residential School to Home/Community:

This presentation gives parents and others ideas and insight into how to transition a child from residential school to home. Topics include: ideas about when to begin

the transition process, how to collaborate services needed with state agencies to obtain appropriate services, how to get support from others, and much more.

A Parents Perspective:

This presentation is for childcare workers, teachers, administrators, and others who work in the residential school field. It offers insight into the challenges parents face when having to place the life of their child in other's hands. Tips for developing collaborative relationships with families are also covered.

As always, feel free to call our hotline at 1-800-672-7084, or email us at pfrr@fcsn.org for more information or support.

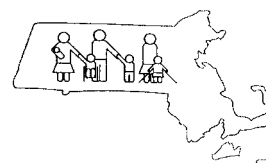
Support Group in Spanish

Project COEP (Community Outreach and Empowerment Project), is a unique parent support project, funded by the Boston Foundation and operated by the Federation for Children with Special Needs. Staff of the COEP Project coordinates support groups for families of children with disabilities. One group, "Familias Latinas Unidas por el Síndrome de Down," (Latino Families United for Down Syndrome) is dedicated to supporting and empowering families of children with Down syndrome. The group meets one Saturday a month from 10 am–12 noon at the Federation in Boston. For more information, please call Diana Rocha at 617-236-7210, ext. 171.



Grupo de Apoyo en Español

The Community Outreach and Empowerment Project (COEP), patrocinado por Boston Foundation en La Federación para Niños con Necesidades Especiales apoya al grupo "Familias Latinas Unidas por el Síndrome de Down." El grupo se dedica a apoyar y aumentar el liderazgo de las familias que tienen niños con el síndrome de Down. Este grupo se reúne un sábado al mes, de 10 a.m. a 12 p.m. en Boston. Para más información, llame a Diana Rocha al 617-236-7210, ext. 171.



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Family TIES Presents: Training Opportunities for Families of Children with Special Needs

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This workshop will offer ideas and information about how to involve your child in your community. This is a wonderful opportunity to hear other parents' suggestions and to learn about the laws that guarantee community access for all children.

For more information about these workshops, or to schedule them, call your Family TIES Coordinator at 1-800-905-TIES.

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The Federation makes Boston Magazine

We were thrilled to discover that the Federation's Gala was recognized in *Boston Magazine's* July 2002 issue.

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To order, call the ASPIRE and ILIAD Partnerships at the Council for Exceptional Children, 888-CEC-SPED (toll-free), 866-915-5000 (TDD), or e-mail service@cec.sped.org

www.ideapractices.org

Discover IDEA: Supporting Achievement for Children with Disabilities received an Honorable Mention in the 2000 Communicator Awards.





Health News

from FAMILY VOICES

at the Federation for Children with Special Needs

2nd Annual Joining Voices Conference

On September 25, Massachusetts Family Voices convened a meeting of 50 parent leaders to discuss issues related to children with special health care needs. The pastoral setting of Ridge Hill Reservation in Needham provided natural, relaxed surroundings for new and old friends to connect and to offer support to one another.

The theme of the day was the Healthy People 2010 goals, a ten-year action plan developed by the Maternal and Child Health Bureau (MCHB) in collaboration with Family Voices, the American Academy of Pediatrics, the March of Dimes and many other private and public organizations. This action plan centers on six goals (see right) whose purpose is to achieve community-based service systems for all children and youth with special health care needs within the

next 10 years. Speakers discussed initiatives currently underway in Massachusetts and other states which target these goals.

The overriding emphasis of each presentation was the importance of family participation in these initiatives. Parents know their child the best and are involved in finding and providing healthcare for their child, as well as participating with professional partners in many initiatives aimed at improving care for this population of children. Health care programs, and policies for children with special health care needs, need input from parents in order to assure that families' needs are met. As Massachusetts focuses on the 2010 goals, there will be many opportunities for parents to participate and ensure that the family perspective is included. If you would like to learn

more about the 2010 goals and opportunities or to get actively involved in these initiatives, call your regional Family TIES coordinator at 1-800-905-TIES.

HEALTHY PEOPLE 2010

1. Families of children with special health care needs will partner in decision making at all levels and will be satisfied with the services they receive.
2. All children with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home
3. All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need.
4. All children will be screened early and continuously for special health care needs.
5. Community-based service systems will be organized so families can use them easily.
6. All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence.

Mass Family Voices Receives Grant

The Center For Health Care Strategies, Inc, a national foundation dedicated to promoting high quality health care services for low-income populations and people with chronic illnesses and disabilities, announced the award of a one year Consumer Action Grant to Mass Family Voices, to begin in October 2002. The grant, "*Building Capacity for Family Partnerships with Managed Care Organizations*" will provide support for the Mass Family Voices listserv, the website, a quarterly newsletter entitled *The Checkup*, and the annual parent leader conference. The grant will also provide funding for Mass Family Voices to work with several health plans to provide information to families of children with special health care needs. This is exciting news for the many dedicated volunteers who have endeavored to help parents in Massachusetts give voice to the issues regarding children with special health care needs!

Join the Family Voices List Serve

If you aren't able to attend conferences but would like to actively participate in Mass Family Voices and network with other families of children with special health needs throughout the state, then en'listing' in the Mass Family Voices list serve may be just the opportunity for you. A list serve is a way to share ideas and exchange information via Internet e-mail. If you have your own e-mail account, or access to one, and are the parent or guardian of a child with special needs, you are welcome to join. Once you enlist, you can send e-mail to and receive e-mail from other families on the list by posting to a single e-mail address. Recent discussion topics have included an exchange of information about support groups, announcements for upcoming conferences and other events, summaries of resource materials and opportunities for family participation. For more information about the Mass Family Voices list serve, please e-mail massfamilyvoices@aol.com.

Website Update: www.massfamilyvoices.org

Massachusetts Family Voices would like to help spread the word about opportunities for parents to participate in learning from, and contributing to, discussions and initiatives about children with special health care needs. Our home page contains a list of paid positions, volunteer opportunities, conferences, events, and surveys. These represent a variety of ways in which parents can get involved. If you have an opportunity to share, please contact Peggy Curran at pcurran@fcsn.org.

FAMILY VOICES

is a national grassroots organization of families and friends speaking on behalf of children with special health care needs. The Federation is one of the founding members of Family Voices and conducts Family Voices projects from the Federation office in Boston.

The Federation Annual Appeal 2002

Dear NewsLine Readers,

We are writing to you because you are currently receiving our quarterly newsletter, *NewsLine*. We are very pleased that we are able to offer this valuable publication and hope that you find the information helpful as well as educational. *NewsLine* is distributed **free of charge** to more than 26,000 families and professionals. Feedback from readers is very positive.

With the economy in a slump and state and federal revenues falling, we have experienced some reductions in funding and anticipate even more over the next year. Therefore, we need your help to ensure that *NewsLine* remains easily available and accessible for families.

If each person who receives *NewsLine* were to contribute just \$10 to cover our production, printing and mailing costs, *NewsLine* would become a self-sustaining and independent publication. Our goal is to continue to provide timely information regarding critical education and healthcare issues.

Market researchers today say that families of 4 spend over \$80 just to go to a movie and buy popcorn. Valuable information, as found in *NewsLine*, can change peoples' lives. It is a terrific bargain.

If each person who receives NewsLine were to contribute just \$10 to cover our production, printing and mailing costs, NewsLine would become a self-sustaining and independent publication.

This year, our annual campaign aims to increase our funds raised by 20 percent over last year's total. Your contribution will help



immensely toward this goal. Please consider a \$10, \$20, \$30 or more contribution today. Help the Federation keep helping families in these difficult days.

Please support *NewsLine* and the Federation. We need your support NOW!

Thanks,

Richard J. Robison

Richard J. Robison
Executive Director

* * * PLEASE MAKE A CONTRIBUTION TODAY * * *

YES! I will help the Federation continue its Mission! I want to support the Federation for Children with Special Needs. Enclosed is my gift.

\$30 \$50 \$100 \$250 \$500 Other \$ _____

Name: _____

Address: _____

City: _____ State: _____ ZIP: _____

Home Telephone: _____ Business Telephone: _____ E-mail: _____

I would like to make my gift by VISA Mastercard

Card Number: _____ Expiration Date _____ Signature _____

My company has a matching gift program.

Company name: _____

Address: _____

I would like to make my contribution in honor of: _____

I would like to make my contribution in memory of: _____

Please include this form with your check made payable to:
Federation for Children with Special Needs, 1135 Tremont Street, Suite 420, Boston, MA 02120
The Federation for Children with Special Needs, Inc. is a 501(c)3 organization.

Now you can donate on line! Visit us on the web at www.fcsn.org.



Federation for Children with Special Needs

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Families Speak Out— Family Voices' Data & Research Activities

Families of children with special health care needs have a wealth of knowledge and experience. Parents are both teachers and students as they share experiences and knowledge with each other as well as teach, and learn from, the professionals who provide services to their children.

Family Voices, a national grassroots coalition of friends and families speaking out on behalf of children with special health needs, believes families have critical roles to play in the collection of information that can enhance the knowledge of families, family leaders, policy makers and child advocates about issues facing children with special health care needs. This information is crucial to improving health policies for our children.

Information, tools and reports about the research and data gathering activities undertaken by Family Voices has now been posted at "Data and Research Activities," a link off the www.familyvoices.org web site. The site provides a wealth of information on these activities, which include collaborations with professionals, collection and dissemination of information and strengthening family leadership roles. Please take some time to check it out.

SAVE THE DATE!



**STRONG FAMILIES IN
a CHANGING WORLD**

**Federation for Children with Special Needs
Annual Conference**

Saturday, March 1, 2003

World Trade Center, Boston

Confirmed Speakers: Stephanie Lee, Director, Office of Special Education Programs, U.S. Department of Education

Charlie Carr, Founder and CEO, Northeast Independent Living Center

Check fcsn.org for updates & online registration



The Federation Gala
May 9, 2003 (see page 2 for details)