



NewsLine

The Federation for Children with Special Needs

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Betsy Anderson

Founding Stories

Betsy Anderson Looks Back

Just as, in 1975, the Federation received the first federal funds to provide training and information on special education for parents of children with disabilities,

in 1985, the Federation was the first parent organization to receive federal dollars to support family involvement in health care. Just as parents' efforts helped open the school-house doors to children with disabilities, parents' efforts helped open the door to a new era in parent involvement in health care as well!

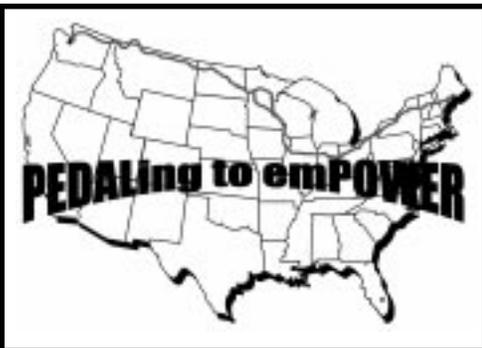
This article by Betsy Anderson is the second commemorating the Federation's Silver Anniversary by highlighting key events and issues that shaped the Federation's advocacy and policy efforts over the years. Although the central focus of the early parent organizing efforts was on passing a special education law, Betsy's story illustrates the critical importance of health care for children with special needs.

In 1969, my family was working to extract our son Michael, born with spina bifida, from Fernald State School. He had been given up at birth, but because of his special needs, papers had never been filed with the state to release him for adoption. We took the tack of bringing him home as a foster child while we worked on adoption, especially getting adoption subsidy laws passed. Michael could walk with crutches, but used a wheelchair some of the time. We quickly saw that our neighborhood school was not accessible and that there were no supports or services available. Also, attitudinal barriers were as great as the physical ones.

“CATEGORICAL” PROGRAMS EXCLUDED MANY

We heard from a friend, a PT, that a new law — called Chapter 766 — was being proposed that would mandate education for all children with special needs. What an exciting and intense time it was! There were only a few parent organizations

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Children with Special Needs and to dedicate the ride to Christopher Bryant, Kathleen's brother and Ralph's son. Christopher, who has Down syndrome, also has many dreams and often faces daunting obstacles in pursuit of those dreams.

Dustin, Kathleen, Ralph, and Liana are asking for sponsorship so that the Federation can continue to help empower parents and families of children with special needs to “bridge the gap between what is possible for some and what is possible for all.” The Federation is delighted to be part of this wonderful adventure and heartily thanks these committed pedalers. See page 15 to read more about the trip and to sponsor the family. The Federation will be tracking the group's progress on its website, www.fcsn.org.

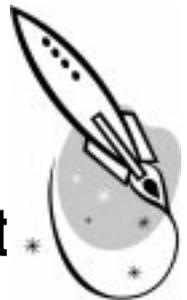
Kathleen Bryant and Dustin Rand finally decided that it was time to realize their dream of biking cross-country, an adventure that had always appealed to them. On May 17, 2000, Kathleen and Dustin, along with Kathleen's father Ralph Bryant and her cousin's wife, Liana Horowitz, will fly to Seattle to begin the journey, rain or shine. Together they realized that they all shared a bigger dream — that all people, particularly all people with special needs, should have the opportunity to realize their own dreams, whatever they may be.

After careful thought and discussion, they decided to use the adventure as an opportunity to raise funds for the Federation for

Bulletin
Parents Learning About Children's Education

Mission: Possible

New Record Set *



The Federation's annual conference, co-sponsored this year with PAL (Parent Professional Advocacy League), Massachusetts Families Organizing for Change, and Family Ties, exceeded last year's record- setting numbers with over 600 parents, professionals, and presenters in attendance. This was the second year in a row that, by the registration deadline, the Federation had already received registrations for a more- than-capacity crowd.

On Saturday, March 18, the crowd gathered at the World Trade Center in Boston to demonstrate their commitment to students with special needs and to participate in over 30 workshops and presentations. Gave the keynote address.

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Legislative & Policy Update

Massachusetts Legislative Update

It has been the season of intense legislative activity in the special education arena, with changes either adopted or threatened that have significant consequences for special education in Massachusetts. Major recent activities, some in the legislative and some in the executive branch, are summarized below in order of their occurrence. As of this writing, there is still hope that action in the Senate can avert the most devastating changes.

March 15. Hundreds rally to preserve Chapter 766

Hundreds of parents, children, and advocates gathered at the State House as the Joint Committee on Education (comprised of Senators and Representatives) heard testimony on proposed changes to decrease special education programs in Massachusetts.

Buffalo Bills quarterback Doug Flutie, whose son has autism, kicked off the rally at 9 AM with an address to the crowd gathered at the Grand Staircase. He spoke passionately about the critical need for high quality education services if children with disabilities are to have a fair chance in life. Mr. Flutie stressed the dire need for the state to contribute a larger share of the funding for special education. Massachusetts currently funds only about 17% of those costs, compared to a national average of 53% in other states.

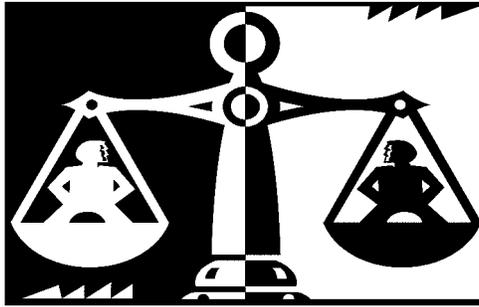
The enthusiastic crowd was encouraged by speeches from Sen. Tolman, Rep. Wolf, and Rep. DeLeo who vowed to do their best to ensure that students continue to be entitled to education that will help them realize their maximum potential.

Following the rally, the crowd filled the Gardner Auditorium where the hearing began at 10 AM. With hundreds signed up to testify, the hearing lasted well into the night, ending after 9 PM. Rich Robison, Federation Executive Director, testified on behalf of the Federation and stayed to the end.

March 28. Board of Education Passes New Regulations

By a vote of 8-0, with 1 member abstaining, the Board of Education voted to adopt newly revised proposed special education regulations. Although parents and advocates

had expressed concerns over *conflicts with both state and federal law*, the Board decided it was time to move forward with the new regulations so that local school systems could receive training on them this spring and implement them in September. At least



one Board Member specifically requested additional time to consider the issues brought forward by the Disability Law Center and the Massachusetts Advocacy Center. However, Board Chairman James Peyser indicated that action was needed immediately.

Members of the Board discussed the possible ramifications of passing new regulations at the same time that the state Legislature is considering its own changes to special education law. Chairman Peyser suggested that some legislators privately would like the Board to vote on the new regulations to force special education reform at some level. Education Commissioner David Driscoll assured members that the new regulations could be adjusted to conform to any changes the Legislature might make to special education law. In the end, the Board decided to make special education reforms at the Department level.

The regulations are due to become effective on September 1, 2000, barring any changes to special education by the Legislature.

April 10. Massachusetts House votes to limit special education protections

Despite the Joint Committee's careful consideration of the testimony of the hundreds of parents as to the need to maintain the protections of the state special education law, the House voted to dramatically change special education law in the Commonwealth. As part of outside language in next year's state budget, the House voted to include several significant aspects of a special ed reform bill previously sponsored by Rep.

Lida Harkins of Needham. Among *many* proposed changes, the House language would:

- Lower our state's special education standard of service from "Maximum Feasible Benefit" to the federal standard known as "free and appropriate public education."
- Implement the federal standard for Independent Evaluation, which allows a school district to refuse a parent's request for an Independent Evaluation.
- Move us to the more restrictive federal definitions of disabilities in determining whether a student is eligible to receive special education services.

The House has voted for these changes in order to save cities, towns, and the state money presently being spent on special education and to limit the number of students who can receive special education services. The Federation opposed these changes in its testimony at the State House hearing on March 15.

Next Steps. Hope lies with the Senate

There is still time for families to protect their children's rights. The Senate begins debate of next year's budget in May. Parents are urged to educate their state senators now about how these changes could affect them and their children.

Encourage them to save Maximum Feasible Benefit and protect all our students. The State House Telephone number is 617-722-2000. If you are not sure who your legislators are, call the Elections Department at 617-727-2828. They will give you the name, phone number, and room number. The directory is also on the Federation web site, along with frequent updates. Readers are urged to go to our web site at www.fcsn.org for more information.

CAMP HOPE IN DUXBURY

is a new residential camp for kids 8-12 who have obsessive-compulsive disorder.

For more information, call Judie Beshwaty at 617-855-3371

From the Executive Director

Two Steps Forward and One Step Back

The war is raging over the rights of students with disabilities to equal opportunity under the law. Our Massachusetts House of Representatives has passed outside language to the next state budget that will significantly reduce our state's standard of services for students with disabilities. For 25 years, Massachusetts has been guided by our state special education law that requires our schools to "assure the maximum possible development in the least restrictive environment of a child with special needs." Since the *David D. vs. Dartmouth* case in 1985, the courts have enforced this standard as the legal standard of the Commonwealth for students with disabilities. (It is interesting to note that helping all children achieve their maximum possible development is the very same language used in the preamble to the Massachusetts Education Reform Act of 1993).

Now, after many unsuccessful attempts, the state has taken two significant steps to reduce this standard. First, the Board of Education removed this language from the new special education regulations passed on March 28, 2000. Second, the House, through outside budget language, voted to move to the lesser federal standard known as "free and appropriate education."

This move should not surprise or shock any of us, as it has been the goal of our political lead-

ership for the past several years. In January 1998 (according to the *Sharon Advocate*), Governor Cellucci declared war on special education following an 18-month legislative commissioned study on this issue. Near the same time, House Speaker Thomas Finneran blamed the "state's special ed law for allowing overly aggressive and pushy parents" to drive up school budgets. He further stated, "The days of riding the gilded Cadillac . . . are over."

The recently released McKinsey Report indicates that changing the standard will save some money, but not very much. The long-term cost of reducing the quality of education for students with disabilities cannot be fully calculated.

Recently a mother wrote and said this: "My own daughter, who is now 32, benefited greatly by the maximum feasible benefit standard and as a result is now employed as a clerk with a prominent accounting firm. When she was 13 years old, the school district took the position that it was a waste of time to continue to teach her how to read and stressed that basic survival skills should be taught in place of academic skills. Their position was based on their belief that a student with an I.Q. of less than 50 would never be able to learn to read. Thanks to our maximum feasible benefit standard, I was able to prevail in this dispute with the school. The school continued to offer reading instruc-



Richard Robison

tion and today she reads and writes in cursive at a 3rd-grade level. Had I allowed the school to drop the reading from her IEP, she would not be employed today. How much more expensive it would be for the Commonwealth if my daughter had not learned to read!"

Thanks to the high standard, this student's life options have been greatly enhanced by her ability to read. She is now a taxpayer and requires very few services from the State Department of Mental Retardation. It is sad and ironic that, as we celebrate this kind of progress, we must fight desperately to protect the rights of all our students to reach their full potential. As this success story illustrates, we have taken two steps forward. If the threatened changes go through, we'll have taken a huge step back.

We in Massachusetts should be proud of our accomplishments. We were first in the nation to raise these expectations, the rest followed. To move to the lower federal standard is a giant step backwards.

Richard J. Robison

Plans to Implement New IEP Proceed

The Massachusetts Department of Education (DOE) is moving forward with plans to implement a revised Individualized Education Program (IEP) form and process in the fall of 2000. In response to these upcoming changes, the Federation has adapted its IEP Workshop to cover the requirements of the revised IEP process and to assist parents in effectively advocating for their children. The Federation recommends that prior to attending Team meetings using the revised IEP process, parents and advocates attend this Workshop.

Throughout April and May, DOE is providing

statewide training for special education personnel on the new IEP. DOE has instructed school districts that the revised IEP form should not be used until September of 2000, with the exception of the 14 sites at which the IEP has been piloted during the 1999-2000 school year.

To a large extent, the revised IEP is based on the federal special education law, Individuals with Disabilities Education Act of 1997 (IDEA '97). IDEA '97 stresses access to the general curriculum, parent and student participation in decision making, and education for children with disabilities in the least restrictive environ-

ment with appropriate supports and services. It is critical, therefore, that parents of children with special needs become familiar with IDEA '97, as well as the Massachusetts special education regulations.

Parents and advocates should be aware that in addition to IDEA '97, portions of the new IEP are contingent upon Massachusetts special education law and regulations, known as Chapter 766. Changes to these regulations were recently passed by the Board of Education. These regulations are presently the subject of debate and changes to them may occur this spring as the result of legislative action. Like the revised IEP form, these new regulations do not go into effect until September of 2000.



Ask Eileen

Empowerment Through Information

by Eileen Souza,
Federation Information Specialist

This column highlights questions that Eileen and the other Federation Information Specialists are most frequently asked.

Dear Eileen,

About a year ago I read your column about special education services for students with disabilities in parochial schools. At that time, you wrote that the rules for providing special education services for children enrolled in parochial schools had changed and that some students might lose related services such as speech therapy. I read in my local paper recently that there has been yet another change! We are sending our son to a parochial school, and he has been receiving speech therapy at the local public school. Is my son in jeopardy of losing speech therapy after this year's IEP?

There have been so many changes and attempted changes from so many quarters lately — the legislature, the Board of Education, the Department of Education — that it's difficult to keep track! You are correct that this is an area where there has been a change, this time from the Legislature with follow-up action from the Board. Essentially the change means that your son should continue to receive the special education services that the IEP Team agrees he needs.

Here's what happened: In January, the Massachusetts Legislature passed a special bill which changed the Department of Education's

policy back to what it was before I answered a similar question a year ago! In addition, new special education regulations passed by the Board of Education on March 28 include provisions which allow students in private parochial placements to continue to receive special education services.

The change that happened a year ago limited the school district's fiscal responsibility to a child *in a private school at private expense* to no more than the amount the district receives from the federal government for special education for an eligible student—about \$480 per child. Schools could pay more if they wanted to, but there was no requirement to do so.

Now, the newly passed legislation and new special education regulations specifically rescind this limitation: "The school district *shall not* withdraw or withhold services for a child solely because the school district has met the spending requirement of the federal law." (28:03 (e)(3)) [Emphasis added].

Overall, Regulation 28:03(e) requires school districts to provide children in parochial schools at private expense "genuine opportunities to participate in the public school special education program consistent with state constitutional limitations." The regulations specify that your son has the right to an evaluation, an IEP, and that a representative of his private school be invited to be a member of the IEP Team.

Further, once the IEP is written, the school district is required to:

"provide or arrange for the provision of the special education described by the child's IEP provided that school districts shall ensure that special education services funded with state or local funds are provided in a public school facility or other public or neutral site." (28:03(e)(3)).

Since your son receives his speech therapy at the public school, there should be no problem with his continuing to do so, provided the Team determines that he continues to need it.

The regulations add a fourth requirement regarding the quality of special education services for children in private schools. They must be "...comparable in quality, scope, and opportunity for participation to that provided to public school children with needs of equal importance." (28:03 (e)(4)).

For a copy of the current regulations which remain in effect until August 31, 2000, as well as the regulations to become effective September 1, 2000, please go to the Federation's website www.fcsn.org/masped.

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NEWS UPDATE

The Board of Education's regulations for Chapter 766 will go into effect on September 1, 2000. They contain many provisions that would dramatically change special education in Massachusetts. Advocates are alarmed and concerned about some changes, which seriously reduce parents' and children's rights. Meanwhile, as *NewsLine* goes to press, the Legislature is considering changes that may have an affect on the regulations and on special education in Massachusetts.

Parents are strongly urged to remain vigilant. To keep abreast of these rapid changes, please check the Federation's website, www.fcsn.org. (See related article, p. 2)

Founding Stories

continued from page 1

then, many of them quite new. For schooling, children were often served in what were called "categorical programs." Heaven help the child who had more than one condition, didn't fit into a category that was being served, or whose disability was deemed "too severe"—local school departments could simply say they couldn't serve them. Waiting lists for special programs or schools were very common.

PARENTS UNITE FOR SUCCESS

As we began to work together in large meetings, parents often gravitated together. We didn't really know each other or each other's groups, nor did we understand the kinds of education and supports different children needed. Some parents, whose children were being served, wanted to protect what they had and were afraid of losing services. Others had nothing to lose because their children had nothing. *No category of children was truly well-served.* Some of us found that the labels that served us well in health settings — spina bifida, cerebral palsy, tuberous sclerosis, cleft lip and palate, etc. — put us at a disadvantage in seeking educational services because our numbers were too small.

To be heard, we had to learn to think more broadly. Our aim became to forge a law that would bring us all into the same tent. We formed the Coalition for Special Education, an ad hoc group of parent and professional organizations specifically to advocate for passage of the law.

At Coalition for Special Education meetings and at huge meetings at the State House, we gradually grew to understand one another's needs and points of view, to respect each other as human beings. This respect was crucial to forging the strong relationships we needed to speak as a unified, powerful voice for the interests of *all* children with special needs. We came to see that our children's conditions were due to chance; we would have been equally adamant advocates no matter what their conditions or labels. Regardless of the specific disability, our children faced enormous problems; much needed to be done, and there were few openings, precedents, laws, or rights for families. Happily, over time, parents became willing to take some risks, think broadly, and move ahead together toward the common goal of passage of Chapter 766.

After the successful passage of the law, it seemed natural for the parent organizations of the Coalition to remain together. Under Martha Ziegler's dynamic and supportive leadership — with lots of hard work still to do! — we became the Federation for Children with Special Needs.

ADVOCACY EFFORTS: HEALTH CARE

Along with understanding more about what we shared in common, across disability labels, came the realization about the many other areas where change was needed. Health was certainly among them. On any given day, we could be addressing issues of health and hospital settings as well as of education. We began to address all sorts of health issues; first among them, though, was *access to information*. There was so little out there for parents, that we found it necessary to write our own factsheets and guidelines. Early titles included "Questions When Surgery is Recommended for Your Child," "IEP Checklist for Children with Special Health Needs," "Decision Making," as well as annotated bibliographies for families. It was common for us to receive calls from parents all over the country looking for any tidbit of information about their child's health condition or health resources.

We also realized that we had no regular ways of meeting and talking with health professionals. It seems hard to believe now, but hospitals and our Department of Public Health did not have advisory committees that we as parents could attend! Perhaps because health professionals were so central to our children's very lives we stressed collaboration as a key strategy in all our efforts.

A serious roadblock to working for change was the lack of health-related funding sources for parents' efforts. But, with Martha's encouragement, we wrote a proposal to fund our growing activities in health. Our first funding came from federal education dollars. We used an "other" category and emphasized that health

On any given day,
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professionals impacted the lives and education of children with special needs. Later, after we got to know the people at the federal Maternal and Child Health Bureau, they became our great allies. We became the first parent organization they funded!

Though there is always so much more to do for and with families, the Federation now has many programs in health that support families' efforts and needs — Family Ties, Family Voices, MassCARE among them.

A SUCCESS STORY FOR MICHAEL, TOO

Meanwhile, Michael is a member of the first generation of young people to benefit from Chapter 766. Before the law was passed, he attended public schools in Cambridge for two years, until the third-grade teacher refused to move her classroom to the first floor! We sent him to the very accommodating (private) Cambridge Friends' School until we moved to Brookline in 1976. By that time Chapter 766 was in effect. In Brookline, Michael attended regular classes — with quite a bit of home and hospital education, too — and graduated from high school in 1982. He has had some college classes and is currently living independently and working for a mortgage company in Portland, Oregon.

Lexington Psychological & Educational Resources

Marsha Chaskelson, PhD, Director

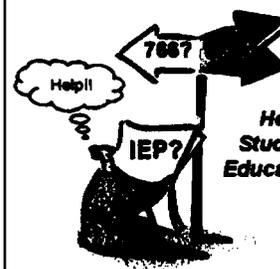
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Making SSI Work:

Tips for SSI Recipients Who Want to Work

Ramona is 22 years old and attends a community college. She dreams of becoming a teaching assistant for children with disabilities. She receives SSI and works part-time at Wendy's. Ramona wants to save money so she can continue her education, pay for a job coach, and buy a car.

Like many new high school graduates, Ramona is worried about how she can save the money she needs to work toward her dream and not lose her SSI benefits. This article answers important questions about how to earn money, save money, and still remain eligible for SSI.

Can I work, save money, and still get SSI benefits?

Yes! The Social Security Administration does allow people who receive SSI to work *and* save money to achieve a vocational goal. You can use an SSI "work incentive" called a PASS (Plan for Achieving Self-Support).

What is a PASS?

A PASS is a program that allows SSI recipients who work to save money by putting it in a special account. The money that is being set aside must be used for things related to reaching a work goal, such as classes that will help you get a new job, hiring a job coach, or transportation to and from work. A PASS must be approved by the Social Security Administration.

Who can have a PASS?

To get a PASS, you must:

- Be over 15 years old,
- Receive SSI (or could qualify for SSI), and
- Have a source of income (other than just SSI).

Will a PASS make me lose my SSI?

No! Generally, to get SSI you must have less than \$2,000 in resources and have limited income (less than \$700/month). The money that you will save in your PASS *will not count as "resources."* *Neither will it count as income.* The money you put into your PASS account will be "excluded" or subtracted from the amount that SSI considers when it figures your earnings. (SSI will not subtract the money from your paycheck. You will still get your entire paycheck, but you will have to put a certain amount into your special PASS account.)

What difference does the PASS make?

With a PASS, you can save money each month to achieve a work-related goal, and receive that much more in SSI. Since SSI does not count the money you are putting in the PASS account, you can *earn* and *keep* more money to achieve your career goals. This means that your total monthly income and savings can be greater.

The PASS not only helps you to keep more of the money you earn, but also lets you save money to help you achieve your career goals, such as classes, car, or job coach, for example.

How can I get a PASS?

- Get form SSA-545-BK from your local Social Security office. It is also available on SSA's web site: www.ssa.gov/work/workincentives.htm
- Think about:
 - * What you need in order to get a better job (e.g., in Ramona's case, to become a teaching assistant);
 - * What assistance you may need to perform your job (e.g., job coach); and
 - * How you would get to and from work and/or school (transportation).
- Write down your specific vocational goals (e.g., to become a teaching assistant, to eventually reduce job coach hours, and to purchase a car).
- Estimate how much time it would take to reach your goals.
- Show how the money you would be saving each month will be used to reach your work goals.
- When you have completed filling out the form, give it to a Certified Rehabilitation Counselor to be reviewed and signed. Any Certified Rehabilitation Counselor can sign your PASS if they know you and can verify that you can probably achieve your work goal. You have a Rehabilitation Counselor assigned to you if you have been referred to the

Massachusetts Rehabilitation Commission (MRC).

- Take the completed form to your local Social Security office to have it approved.

Remember:

Anyone can help you fill out the PASS form: a social worker, a teacher, a friend, a vocational counselor, etc.

This article is from Opening Doors, a collaborative project of the Institute for Community Inclusion, the Federation for Children with Special Needs, and the Disability Law Center. The purpose of the project is to increase the use of SSI work incentives. For more information about PASS, or for your local Social Security Office, call:

The Social Security Administration
(800) 772-1213

If you have questions related to SSI and SSI work incentives, or suggested topics for future newsletters, please contact: Elena Varney, Institute for Community Inclusion, Children's Hospital, 300 Longwood Avenue, Boston, MA 02115; (617) 355-8022.

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Haciendo que el Seguro Suplementario de Ingresos (SSI) trabaje:

Consejos para personas que reciben SSI y que quieren trabajar

Ramona tiene 22 años y asiste a una Universidad comunitaria. Ella sueña con llegar a ser una profesora asistente para niños con necesidades especiales. Ella recibe SSI y trabaja medio tiempo en Wendy's. Ramona quiere ahorrar dinero para continuar su educación, pagar un capacitador, y comprar un carro.

Como muchos alumnos graduados de la secundaria, Ramona está preocupada acerca de cómo va a ahorrar el dinero que necesita para realizar su sueño y a la vez no perder los beneficios de SSI.

¿Puedo trabajar, ahorrar dinero y todavía recibir los beneficios del SSI?

Sí! La Administración del Seguro Social permite a las personas que reciben SSI trabajar y ahorrar dinero con el objeto de alcanzar sus metas vocacionales. Usted puede usar un "incentivo para trabajar" llamado PASS (Plan for Achieving Self-Support) Plan para Alcanzar Auto-Sostenimiento.

¿Qué es un PASS?

Un PASS es un programa que permite ahorrar dinero con el propósito de ponerlo en una cuenta especial a aquellos que reciben SSI y trabajan. El dinero que es separado tiene que ser utilizado para alcanzar las metas de trabajo propuestas, tales como clases que le ayudarán a buscar un nuevo trabajo, contratar un capacitador, tener acceso a transporte desde o hasta el trabajo. Un PASS tiene que ser aprobado por la Administración del Seguro Social.

¿Quién puede tener un PASS?

Para obtener un PASS usted tiene que:

- Ser mayor de 15 años.
- Recibir SSI (o ser elegible para tener SSI), y
- Tener una fuente de ingreso (otra diferente a la del SSI).

¿El PASS me hará perder mi SSI ?

No! Generalmente para obtener un SSI usted tiene que tener recursos por menos de \$2,000 y tener un ingreso bajo (menos de \$700 al mes). El dinero que usted ahorrará en su PASS no contará como parte de sus "recursos." Tampoco será contado como parte de su ingreso. El

dinero que usted pone en la cuenta de su PASS será "excluido" o deducido de la cantidad que el SSI considere cuando sus ingresos hayan sido establecidos. (El SSI no deduce el dinero de su cheque de pago. Usted sigue recibiendo su cheque de pago completo, pero tendrá que poner cierta cantidad en su cuenta especial PASS).

¿Qué diferencia hace el PASS?

Con un PASS usted puede ahorrar dinero cada mes con el objeto de alcanzar una meta relacionada con su trabajo, y recibir más en su SSI. Como el SSI no cuenta el dinero que usted está poniendo en sus cuenta PASS, usted puede *ganar y mantener* más dinero para obtener las metas de su carrera. Esto significa que su ingreso total mensual y sus ahorros serán mayores.

El PASS no sólo le ayuda a conservar el dinero del que usted gana, sino que también le permitirá ahorrar dinero que le ayudará a alcanzar las metas de su carrera, tales como clases, o un capacitador, por ejemplo.

¿Cómo puedo obtener un PASS?

- Obtenga la forma SSA-545-BK en la oficina local del Seguro Social. Esta forma también está disponible en la página de Internet de la Administración del Seguro Social: www.ssa.gov/work/workincentives.htm
- Piense acerca de:
 - * lo que necesita para obtener un mejor trabajo (Ejemplo, en el caso de Ramona, llegar a ser una profesora asistente);
 - * la ayuda que puede necesitar para realizar su trabajo (Ejemplo, un capacitador); y
 - * cómo se transporta hasta su trabajo y/o universidad (Transporte).
- Escriba sus metas vocacionales específicas (Ejemplo: convertirse en una profesora asistente, reducir sus sesiones de capacitación, y comprar un carro).
- Calcule cuánto tiempo le tomaría alcanzar sus metas.
- Muestre cómo será usado el dinero que usted estaría ahorrando mensualmente para alcanzar las metas de su trabajo.

- Cuando haya terminado de llenar la forma, entréguela a un Consejero de Rehabilitación Certificado para que ésta sea revisada y firmada. Cualquier Consejero de Rehabilitación Certificado puede firmar su PASS si éste le conoce a usted y verifica que probablemente usted puede alcanzar su meta de trabajo. A usted se le ha asignado un Consejero de Rehabilitación Certificado si usted ha sido referido/a a la Comisión de Rehabilitación de Massachusetts (MRC).
- Lleve la forma completa a la Oficina del Seguro Social local para que ésta sea aprobada.

Recuerde:

Cualquier persona puede ayudarle a llenar la forma para obtener su PASS: Un trabajador social, un profesor, un amigo, un consejero vocacional, etc.

Este artículo fue tomado de "Abriendo Puertas" (Opening Doors), un proyecto de colaboración de Institute for Community Inclusion (el Instituto para Inclusión Comunitaria), the Federation for Children with Special Needs (la Federación para Niños con Necesidades Especiales), e Disability Law Center (el Centro para la Ley del Deshabilitado). El objetivo de este proyecto es aumentar el uso de incentivos para trabajar del SSI. Para mayor información relacionada con PASS, o para saber sobre la Oficina del Seguro Social local, llame:

**Administración del Seguro Social
(800) 772-1213**

Si usted tiene preguntas relacionadas con SSI e/o incentivos para el trabajo del SSI, o sugerencias para boletines futuros, por favor contacte: Elena Varney, Instituto para la Inclusión Comunitaria, Children's Hospital, 300 Longwood Avenue, Boston, MA 02115; (617) 355-8022.

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Fazendo o SSI Funcionar:

Dicas para beneficiários do SSI que querem trabalhar

Ramona tem 22 anos e assiste aulas numa faculdade comunitária. Ela sonha em vir a ser uma professora assistente de crianças portadoras de deficiência. Ela recebe o SSI [Renda de Seguridade Social] e trabalha meio-período na Wendy's. Ramona quer economizar dinheiro, podendo, assim, continuar seus estudos, pagar por um orientador profissional e comprar um carro.

Como muitos outros recém-formados do curso colegial (high school), Ramona está preocupada em como poupar o dinheiro necessário para trabalhar em busca do seu sonho e, ao mesmo tempo, não perder os benefícios do SSI. Este artigo responde a questões importantes sobre como ganhar e economizar dinheiro e ainda permanecer elegível para o SSI.

Eu posso trabalhar, economizar dinheiro e, ainda assim, receber os benefícios do SSI?

Sim! O Social Security Administration (Administração de Seguridade Social) de fato permite que as pessoas que recebem o SSI trabalhem e poupem dinheiro para atingir um objetivo vocacional. Você pode usar o work incentive (incentivo ao trabalho) do SSI chamado PASS (Plan for Achieving Self-Support/ Plano para atingir a Auto-suficiência).

O que é PASS?

PASS é um programa que permite aos beneficiários do SSI que trabalham a pouparem o seu dinheiro, depositando-o numa conta especial. O dinheiro que está sendo economizado deve ser usado para coisas relacionadas à obtenção de um objetivo de trabalho, tais como aulas que ajudarão a conseguir um novo emprego, contratar um orientador profissional, ou transporte para ir ao trabalho. O PASS deve ser aprovado pelo Social Security Administration.

Quem pode obter o PASS?

Para obter o PASS, você deve:

- Ter mais de 15 anos de idade,
- Receber o SSI (ou que possa qualificar-se para o mesmo), e
- Ter uma fonte de renda (outra que não apenas a do SSI)

Obtendo o PASS eu perco o meu SSI?

Não! Geralmente, para obter o PASS, você deve possuir menos do que \$2.000 dólares em recursos e ter uma renda limitada (menos de \$700 dólares/mês). O dinheiro que você guardar no seu PASS não será contado como recursos. E nem será contado como renda. O dinheiro que você depositar na sua conta do PASS será excluído ou subtraído

do total que o SSI considera quando ele calcula os seus recebimentos. (O SSI não subtrairá o valor do seu paycheck (cheque de pagamento). Você receberá, de fato, o valor total de seu ordenado, mas você terá de depositar uma certa quantia na sua conta especial do PASS.)

Que diferença faz o PASS?

Com o PASS, você poderá poupar dinheiro todos os meses para realizar um objetivo relacionado ao trabalho, e receber aquele tanto mais do SSI. Uma vez que o SSI não conta o dinheiro que você deposita na conta do PASS, você pode ganhar e guardar mais dinheiro para a realização de seus objetivos de carreira.

O PASS não apenas ajuda-lhe a guardar mais do dinheiro que você ganha, mas, também, concede que você poupe dinheiro para ajudá-lo a alcançar seus objetivos profissionais, como aulas, carro ou orientação vocacional, por exemplo.

Como eu consigo um PASS?

- Obtenha o formulário SSA-545-BK do seu escritório local do Social Security. O mesmo também está disponível no website do SSA: www.ssa.gov/work/workincentives.htm
- Pense nisso:
 - * O que você precisa em ordem para obter um emprego melhor (no caso de Ramona, acima, tomar-se uma professora assistente);
 - * Que tipo de assistência você possa precisar para o desempenho de seu trabalho (p. ex. orientação profissional); e
 - * Como você vai e volta para o trabalho e/ou escola (transporte).
- Escreva seus objetivos vocacionais específicos (p. ex. tomar-se um professor(a) assistente, eventualmente reduzir as horas de orientação profissional, comprar um carro).
- Avalie quanto tempo seria necessário para o alcance de suas metas.
- Explique como o dinheiro que você estaria economizando todo mês será usado para atingir seus objetivos de trabalho.
- Quando você tiver preenchido o formulário completamente, entregue-o ao Certified Rehabilitation Counselor (Consultor Certificado de Reabilitação) para ser revisado e assinado. Qualquer Certified Rehabilitation Counselor pode assinar o seu PASS, se eles lhe

conhecem, e possam verificar que você provavelmente atingirá os seus objetivos de trabalho. Você tem um Rehabilitation Counselor designado para você se você já foi encaminhado ao Massachusetts Rehabilitation Commission (MRC). (Comissão de Reabilitação de Massachusetts)

- Leve, por fim, o formulário preenchido para o seu escritório local do Social Security para que seja aprovado.

Lembre-se:

qualquer pessoa poderá ajudá-lo(a) a preencher o seu formulário do PASS: uma assistente social, um professor, um amigo, um orientador vocacional, etc.

Este artigo é uma realização do Opening Doors (Abrindo Portas), um projeto em colaboração com o Institute for Community Inclusion, a Federation for Children with Special Needs, e a Disability Law Center. A proposta do projeto é aumentar o uso do work incentives do SSI. Para maiores informações sobre o PASS, ou para o seu escritório local do Social Security, telefone: **The Social Security Administration (800) 772-1213**

Caso você tenha alguma questão relacionada ao SSI e ao SSI work incentives, ou queira sugerir temas para os próximos informativos, por favor contacte: Elena Varney, Institute for Community Inclusion, Children's Hospital, 300 Longwood Ave, Boston, MA, 02115 (617) 355-8022



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National Council on Disability Issues Startling Report

"We concur with one of the major premises of this report: parents should not bear the burden of enforcement just to get their children an education."

– US Department of Education, in Response to NCD Report

On January 25, 2000, the National Council on Disability (NCD) issued its independent analysis of over two decades of federal enforcement of IDEA, Part B, the federal special education law. In its report, "Back to School on Civil Rights: Advancing the Federal Commitment to Leave No Child Behind," the NCD reveals startling and disturbing findings. Overall, the NCD reports that "federal efforts to enforce the law over several Administrations have been inconsistent, ineffective, and lacking any real teeth." Failures to ensure local compliance with federal special education requirements have persisted over many years and continue today to be widespread. In fact, the NCD found that *every single state was out of compliance with IDEA requirements to some degree.*

In another key finding, the report confirms what parents across the nation know firsthand: *Enforcement of the law is too often the burden of parents who must invoke formal complaint procedures and request due process hearings to obtain the services and supports to which their children are entitled under law. Furthermore, many parents with limited resources are unable to challenge*

violations successfully when they occur.

Massachusetts was one of six states singled out

for discussion in a section entitled "Persistence of Noncompliance Over Time." A 1995 letter to the Mass. Department of Education from the U.S. Department of Education (OSEP) listed five continuing deficiencies that were identified in 1991 and not corrected, in spite of the Mass. DOE documentation to OSEP that the deficiencies had been corrected.* Deficiencies were in areas of timelines for resolving complaints, placement in least restrictive environment, monitoring, holding annual IEP meetings, and distribution of funds to local districts based on approved applications. **

Although the findings of the NCD report are disturbing, parents of children with disabilities are supportive of the law. Through IDEA, thousands of children have graduated and have gone on to live successful lives. But now, the nation needs to bring justice to students with disabilities and their parents.

To this end, the report includes 52 recommendations. Because of the tremendous burden on parents to force implementation, the report recommends that the US Department of Education provide additional funds for advocacy training programs, resources, and services to students with disabilities and their parents. The report calls for lawyers to be available at every state Parent Training and Information (PTI) Center [the Federation is the Massachusetts PTI], able to provide competent legal advice to students with disabilities and their parents in

advocating for their rights. (For a complete copy of the report, go to www.ncd.gov/newsroom/publications/backtoschool_1.html or call 202-272-2004.)

From July through September 2000, the NCD will conduct 15 community briefings on critical issues for people with disabilities. The Federation and the National Parent Network on Disability (NPND) will co-sponsor an NCD briefing at the Federal Reserve Bank, Boston, on September 19 from 10 AM to 4 PM. Parents are invited to testify. For more information, contact the Federation at (617) 236-7210 .

NPND has developed a ToolKit based on the NCD report. It provides guidance on how to become involved in advocating for stronger enforcement of IDEA. The ToolKit is available on the NPND website: www.npnd.org, or by calling NPND at 202-463-2200.

The NCD is an independent federal agency composed of 15 members appointed by the President and confirmed by the US Senate. NCD's purpose is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all people with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

* OSEP has conducted a more recent review of Massachusetts special education. Completed in 1999, OSEP's report, 15 months overdue, has yet to be released.

** **Ed.'s note:** In light of current efforts to reduce the state special education standard of "maximum feasible benefit" to the federal standard of "free and appropriate public education (FAPE)," it is notable that the report cites Massachusetts for failure to even meet the federal FAPE standard. In other words, just to comply with the federal standard, the state would need to improve implementation of special education.

* * * JOIN THE FEDERATION TODAY * * *

Become a Member!

The Federation would like to take this opportunity to thank all of our members for their invaluable support. Not only does your membership make a difference to us and all the families we serve, it gives you:

- **A Stronger Federation**
- **Access to current information**
- **Networking opportunities with other parents**
- **Quarterly issues of NewsLine.**
- **A 10% discount on all Federation publications, conferences, and workshops.**

I want to join the Federation for Children with Special Needs. Enclosed are my membership dues. Please send me the one-year subscription to *NewsLine*, and other member benefits.

Please make checks payable to: Federation for Children with Special Needs, 1135 Tremont Street, Boston, MA 02120. Thank you!

Please enroll me in the following Federation membership(s):

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Patron	<input type="checkbox"/> \$500	Professional	<input type="checkbox"/> \$50	
Sponsor	<input type="checkbox"/> \$250	Family/Individual	<input type="checkbox"/> \$30	

Name _____

Address _____

City, State, ZIP _____ Email: _____

Enclosed is my check for \$ _____ Please charge \$ _____ MC VS

Card # _____ exp. date _____

Signature _____

All contributions in excess of \$4.00 are fully tax deductible.

Early Childhood Corner



Highlighting information of interest to parents of children under five and their professional partners, particularly Early Intervention service providers. Sponsored by the Federation's Early Intervention Training Center.

Principles of Family-Centered Care

(and how to strive to apply them in early intervention!)

Recognize that the family is the constant in the child's life, while the service systems and personnel within those systems change.

Families are the center of a young child's life. Family members surround themselves with the people they need in the life of their child and family, including extended family, community members, professional and service providers. Early interventionists offer the family their unique blend of knowledge about child development and strategies to help the family support their child's growth at home and in the community. Early interventionists also help families make the transition to future services.

Facilitate family-professional collaboration at all levels of intervention.

Early interventionists are expected to develop partnerships with families that are based on mutual respect and open communication. Early interventionists set the stage for communication in which both the families' and service providers' input is valued so that families can share information with everyone who supports their child.

Honor the racial, ethnic, cultural and socioeconomic diversity of families.

Early interventionists are expected to use each family's definition of who makes up the family; respect family roles and ways of making decisions; be sensitive to each family's ideas about disability; and listen for each family's preferences for service and supports.

Recognize family strengths and individuality and respect different methods of coping and adjustment.

When developing their Individualized Family Service Plan (IFSP), a family identifies their strengths and resources. Early interventionists offer their help in this process and then work to be sure that services are provided in ways that are comfortable for the family.

Share with parents, on a continuing basis and in a supportive manner, complete and unbiased information.

In order for partnerships to work, all partners must have the same information.

Early interventionists:

- Offer their knowledge.

- Help families understand all technical language and jargon.
- Explain all information and options to a family to help in making decisions for their child, and assist the family in evaluating the pros and cons of each option.

Families:

- Help this happen by asking questions freely.
- Share information about their family and their dreams for their child.

Encourage and facilitate family-to-family support and networking.

Early intervention programs provide opportunities for families to share with each other. This networking offers many benefits to families, such as information on disabilities, community services and working with professionals; friendship; helpful tips about how to work within the system; a listening ear; ideas about getting through the tough times; and a parent point of view.

Understand the developmental needs of infants, toddlers, children and their families as they relate to life in the community.

Families live, work and play in communities. Early interventionists help family members participate in everyday community activities with their child(ren) by helping them discover or create the supports and approaches that make it possible.

Implement comprehensive policies and programs that provide emotional and financial support to meet the needs of families.

Families are welcome participants in all aspects of the early intervention system, from individual family service planning to state policy development. Supports such as stipends, travel and child care reimbursements, mentorships and training in effective participation make it easier for families to participate. Family participation promotes policies which continue to support family needs.

Design accessible early intervention systems that are flexible, culturally competent, and responsive to family-identified needs.

Family participation in policymaking within the early intervention system ensures that the needs of families will be recognized. Policies are developed which support an individual program's flexibility in meeting the needs of its own community while assuring quality services across the state. The system responds to family needs by supporting approaches such as flexible scheduling of services, coordinating with day care and other community service providers and hiring culturally diverse staff. All of these approaches help accommodate differing family needs.

From: *Working Together: Early Intervention Family Participation Resources*

Produced by the Family Participation Task Group of the Massachusetts Early Intervention Interagency Coordinating Council in collaboration with the Massachusetts Department of Public Health Jan. 1997

Early Intervention Workshop Schedule

June 2000

DATE	WORKSHOP	LOCATION
June 1	Welcome to Early Intervention	Boston
June 7	Welcome Back to EI	Springfield
June 14	Service Coordination	Worcester

The workshops above are available to staff and families involved in Early Intervention and to other early childhood personnel. For more information contact Sarai Marthone at 236-7210 ext. 159, marthone@fcsn.org



Health News

from FAMILY VOICES

at the Federation for Children with Special Needs

Family Voices Announces Massachusetts Coordinator

Family Voices announces that its new Massachusetts State Coordinator is Polly Sherman, who is also Director of Family TIES at the Federation for Children with Special Needs. Located in the regional offices of the Massachusetts Department of Public Health, Polly and the six Family Ties coordinators are parents of children with special needs who help families by providing information and support on health issues. Now, by contacting them, families will also be linked to the national organization.

Family Voices was established in 1992 and serves as a national, grassroots network of families and friends speaking on behalf of children with special health care needs. For more information, to become part of the network, and to be placed on the mailing list, contact the Family TIES Coordinators by calling 1-800-905-TIES (8437) or returning the form on the right. Polly will be working with the Family Voices staff members on projects located at the Federation for Children with Special Needs. You may also want to check out the new Massachusetts Family Voices webpage at massfamilyvoices.org. You will be able to link from there to the national Family Voices site at familyvoices.org.

Join Massachusetts Family Voices!

Membership is free, but we accept donations.

Please complete this form and mail to: Family Voices at the Federation for Children with Special Needs, Attn: Polly Sherman, 1135 Tremont St., Suite 420, Boston, MA 02120.

Name _____

Tel.# _____

Address _____

City _____

State _____ ZIP _____

Email _____

PAL News

Human Rights Award

Congratulations to Assistant Director of PAL, Lisa Lambert, who received the Human Rights award from the Department of Mental Health! She was nominated by Cheryl Celephano, a long-time education advocate who met Lisa over 6 years ago. Cheryl cited the following accomplishments, among others, in nominating Lisa:

- Presentations at conferences on how to file legislation.
- Participation since 1994 in the parity bill.
- Recognition from Marylou Sanders, Commissioner of the Department of Mental Health, for involvement with the mental health coalition.
- Involvement with the Five Fundamental Rights Bill as it applies to children.
- Filing of a letter with the Department of Education around use of restraints.
- Co-authorship of a crisis manual for parents.
- Establishment, with two others, of a children's mental health week focusing on education to reduce stigma.

Past awards have recognized the efforts of individuals working in the adult mental health field.

This year's award—given for the first time to an advocate for children—represents a great recognition of the mental health needs of children. Congratulations Lisa!

Children's Mental Health Week

May 7-13, 2000, was the 5th annual celebration of Children's Mental Health Week in Massachusetts. This campaign aims to promote education and awareness while decreasing the stigma children and their families often experience when a child has mental health concerns. Children's Mental Health Week is a time to focus on the need for everyone in the community to join together to ensure that all children experience, now and in the future, the most productive lives possible.

The ACTIVITIES of Children's Mental Health Week included:

- Statewide distribution of informational posters
- A research presentation by Simmons College School of Social Work
- Distribution of a special edition of PALnews
- Introduction of PAL lapel pin
- Introduction of PAL Website: www.ppal.net
- Many area-based activities throughout the PAL network

Many thanks to members of the Family Support Network of Western Mass for assistance with this year's campaign. And special thanks to Gael K. Bryant for creating the beautiful design for the PAL pin and to Laura Murphy-Glove for her work on the newsletter.

PAL is the Massachusetts Chapter of the national Federation of Families for Children's Mental Health and works in collaboration with the Federation for Children with Special Needs. For more information or to order PAL Pins and other materials, contact the PAL office at e-mail: pal@fcsn.org, or call (617) 227-4886.

Family TIES Announces FREE Resource Directory

Just off the press in March, Family TIES' third edition of "Resources for Families of Children with Special Needs" is now available free upon request. The Directory lists state and regional contact information on state agencies, parent networks, as well as organizations providing services such as adaptive equipment and assistive technology, child care, legal services, respite care and family support, and recreation, among others.

For your copy, call 800-905-TIES (8437), or download it from the web at [web at www.massfamilyties.org](http://www.massfamilyties.org).



MISSION: POSSIBLE KEYNOTE STORIES

by *Miryam Wiley*

In his trademark style of poignant stories and an inviting sense of humor, keynote speaker Dan Wilkins urged everyone to follow his example and keep talking. "It's so important for us as people with disabilities and family members who 'get it' to share our stories," Wilkins said, "so that everyone else starts to get it as well."

Though a car accident provided a sudden introduction to the world of wheelchairs, Wilkins soon became aware of the true obstacles in his life. "I have a disability. I broke my neck in a car accident a long time ago. But I'm only handicapped when I find a barrier that prevents me from reaching a goal," he said. "It may be a curb, it may be a narrow door way, it may be an inaccessible bathroom. 'Oh, you guys have to go to the bathroom too?'" In sharing his frustrations, Wilkins never loses sight of humor, a coping strategy he recommends.

Plenty of people simply don't seem to see their role in helping others belong. "When I tell a guy that he needs to get rid of a step in front of a restaurant, he says, 'Why? We don't get any wheelchairs here.'" Wilkins shared his sadness in seeing how young children, ready to cope with their differences in positive ways, suddenly become withdrawn and depressed because people around them do not include them once they realize they're different.

He told a story of a four-year-old boy who proudly wore his silver bracelet to advise others about his seizures. The boy candidly answered anyone who asked that he wore the bracelet because of his seizures. But soon enough he noticed that people stopped talking to him and he realized his difference wasn't accepted. "There are many of us who, like the little boy, have learned the hard way that what others don't know can't hurt you," Wilkins said.

Despite some gains toward greater inclusion of people with disabilities, Wilkins stressed the enormous amount of work yet to be done. "I hope you don't mind me saying this, but the first 95 percent of the last millennium really stunk for people with disabilities," he said. "When we weren't killed outright or left on hillsides to die, we were neglected, burned as witches or monsters, raped, killed through euthanasia in the name of compassion, or left in institutions to die."

Even today, amidst a booming economy and low unemployment, there is still little room for people with disabilities. "Our unemployment figures are 60 to 70 percent," he said, "despite media broadcasts that, 'in America, everybody who wants a job, has a job.'"



Dan Wilkins,
Keynote speaker

He encouraged everyone to keep trying to find common ground. "When you encounter a teacher or a professional who is not getting it, try to find common ground. Our best common ground is our shared oppression. There is so much power there."

A proud father of a one-year-old boy, Wilkins said that "living with a disability is not a detriment, it is not a tragedy," as many seem to insist. He reminded all that plenty of influential achievers in our society, such as President Roosevelt, did it all from wheelchairs. Making that point clearly to society at large is a big task and, among many other things, will require plenty of storytelling. "Let us listen to each other's stories and embrace our commonalities," he said.

FACES FROM THE CONFERENCE



Several state officials addressed the participants. From left to right are Gerry Morrissey, Commissioner, DMR; Deborah Klein Walker, Associate Commissioner, DPH; and Marian Freedman Gurspan, Statewide Children's Coordinator, DMH.





The Portuguese Outreach Program

at the Federation and Parents' PLACE were well represented at the Annual Conference with workshops for families and professionals, a resource table, and information specialists prepared to assist the Portuguese-

speaking attendees. Distinguished guests on networking session panel included Marcia Loureiro from the Brazilian Consulate, Donalda Silva from the Department of Public Health, Ilene Farah, speech therapist, and Katia Galvao, a bilingual parent advocate. One highlight was the presentation of Roberto Maranhao, a puppeteer from New Jersey. Besides a lunch-hour presentation amidst a bevy of networking enthusiasts, Maranhao used his puppets to demonstrate assertive parent roles at an IEP meeting during the Effective Communications Workshop. Maranhao has a list of presentations in English, Spanish, and Portuguese on such topics as inclusion, substance abuse, and bicultural and bilingual education for organizations, schools, or church groups. Please call Sandy Blanes for more information at 800-331-0688, x144.

Mission Possible: New Record Set continued from page 1

The audience was inspired by his quick wit and thoughtful presentation, while genuinely moved by his courage and determination as he described the discrimination and attitudinal barriers he faced which are so familiar to people with disabilities. (See related article by Miryam Wiley, previous page).

Following the keynote, participants selected from among over 30 workshops, including a full selection of workshops in either Spanish or Portuguese. Simultaneous translations into Spanish, Portuguese, and American Sign Language were available.

The Federation also recognized the work of parent leaders across the state with Parent Leadership Awards presented to the following parents: Mary Quigley, former Information Specialist for the

Federation in Western Massachusetts, and Linea Luck Pearson, former Family Ties Coordinator for Central Massachusetts.

State officials also addressed the conferees, among them: Commissioner Gerald Morrissey, Department of Mental Retardation; Associate Commissioner Debbie Klein-Walker, Department of Public Health; and Marion Freedman-Gurspan, Director of Children's Services for the Department of Mental Health.

Over 100 presenters, volunteers, and exhibitors made this year's conference one of our largest and most successful ever. Thanks to all who took the time to participate and embrace the Mission Possible!

NewsLine

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The Federation for Children with Special Needs

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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Ed DeNoble, Linda Downer, Jack Foley,

Robin Foley, William Henderson,

Anne Howard, Deborah Smith-Pressley,

Miryam Wiley



CLOCKWISE FROM LEFT:
 Linea Luck Pearson received a Parent Leadership Award from Polly Sherman, Family Ties Director, for seven years of service as Families Ties Coordinator for central Massachusetts;
 Mary Quigley received a parent Leadership Award from Rich Robison, Executive Director, for many years of service to families in western Massachusetts;
 Martha Ziegler, Founding Executive Director, received the Council for Exceptional Children's Public Policy Award from Nancy Safer, Executive Director of CEC, Washington, D.C.

PEDALING to emPOWER

The Plan

From coast to coast, over three mountain ranges, averaging 50 miles a day, camping out rain or shine, Ralph Bryant, Kathleen Bryant, Dustin Rand, and Liana Horovitz will be realizing a dream: a ride across America for all children with all abilities. Below are excerpts from PEDALING to emPOWER: The Plan which describes the adventure.

The planning process started about a year before the estimated start date. We estimated the cost of equipment we were going to need, transportation to and from the end points, food, camping, repairs and, of course, the fun we wanted to have along the way. Next we set out buying all of the gear we would need for the trip.

Jobs? How did we get the time off? Kathleen and Dustin took the brute force method and quit their jobs after

giving a few months notice. Ralph crossed his fingers and asked for a substantial leave of absence. He lucked out and was granted his request and then tacked on his accumulated vacation time. Liana works in the school system so she will spend her summer vacation on the trip.

So now we have the time off and all of the equipment. What to do next?

BIKES AND BAGS: Kathleen and Dustin will be riding the tandem with the BOB (Beast of Burden) trailer shown above. Ralph and Liana will be riding their own individual Bianchi, Volpe touring bikes. The bikes we choose are designed for road riding and touring.



TRAINING: The best way to train for a long distance bike trip is to ride your bike. So that is what we are doing. We plan on biking 3 – 4 days during the week, 10 –20 miles a day. On weekends we are planning longer rides, 30 – 60 miles. We would like to do a few overnight trips to test our camping gear and what it is like to ride a bike with an extra 50 lbs. of gear. By the first weeks in May we would like to be biking 150+ miles a week.

THE ROUTE: 4,500 miles — From the Puget Sound to fishing villages in Maine, the Northern Tier crosses three mountain ranges — the Cascades, Rockies, and Adirondacks. Along the way, the route passes through Glacier National Park, the headwaters of the Mississippi, and Amish country. We will

be stopping along the way to see points of personal interest and visit friends in various towns. If you think you might be on our route and you are brave

enough to want 4 somewhat dirty bikers to stay a night in your house, yard, barn, etc., please let us know.

STARTING THE TRIP: We bought one-way plane tickets to Seattle, Washington, to begin the trip. May 17th we will be boxing up the bikes and stepping onto the plane. After arrival in Seattle we will be staying in a local Youth Hostel for the first night. The following morning, after reassembling the bikes, we will be heading to the ferry to take us to the San Juan Islands. Once off the ferry, the pedaling will commence and we will be biking across the US!

EATING AND SLEEPING: We will be bringing tents, sleeping bags and sleeping pads so we can

camp for most nights on the trip (yes, even in the rain). Of course there will be nights when a motel or inn is on the agenda for a guaranteed good night's rest.

On this trip, eating is one thing that cannot be overdone, because we will be burning thousands of calories each day. We will be bringing two stoves, three pots, bowls and utensils for making breakfast, lunch and dinner each day. We will try to buy dinner and the next day's breakfast and lunch just before we roll into camp. This will minimize the amount of weight we have to carry during the day.

COMMUNICATION: During the trip we will want to keep in touch with family and friends and also be prepared for emergencies. We will set up mail drops in specific towns so people can mail us letters, food, supplies and anything else they might think we would enjoy. We will also be calling and mailing letters and postcards along the way to keep in touch. We will also have a cell phone in case of an emergency. In addition, the Federation will be posting our progress on their website <http://www.fcsn.org>.

FINISHING THE TRIP: Three months after starting the trip in Seattle, we will be riding into Bar Harbor, Maine. The exact duration of the trip is difficult to calculate precisely, due to weather, strength, injuries, etc. We will have ridden approximately 4500 miles across mountains, plains and deserts and will be reuniting with family and friends for some rest and relaxation!

Consider making a donation to help the group on their way! Already friends of the Federation have donated nearly \$4,500 — that's \$1.00 per mile! Wouldn't it be great if they were pedaling for \$2.00 every mile?

Sponsor Form

PEDALING to emPOWER

Yes, I will help empower parents and families of children with special needs to access the services that exist and help create the ones that don't.

DONATION CATEGORY

AMOUNT

I'm a student	\$15
I'm not a student, but still paying off loans	\$25
Phantom Rider(1 cent a mile)	\$43.10
Phantom Tandem Rider (2 cents a mile)	\$86.20
Donation Champion	\$100
We will pull you across the country in our trailer	\$1000
Create-A-Category	\$_____

Check enclosed (made payable to Federation for Children with Special Needs)

MC/VS/AmEx #: _____ Exp date. _____

Cardholder Name: _____

Name/Company: _____

Address: _____

City/State/ZIP: _____

Phone: _____

Date: _____

Please send donations to the following address:
 PEDALING c/o Federation for Children with Special Needs
 1135 Tremont Street, Boston, MA 02120



Federation for Children with Special Needs
1135 Tremont Street, Ste. 420
Boston, MA 02120
617-236-7210 Voice/TDD
MA Toll Free 800-331-0688
email: kidinfo@fcsn.org
web: www.fcsn.org

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Federation for Children

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with Special Needs

*25 years of
Parents Helping Parents*

Federation for Children with Special Needs 25th Anniversary Gala and Fund Raiser

As we go to press, we are putting the final touches on the Federation's 25th Anniversary Gala. On May 12, over 400 guests will arrive at the Cambridge Sonesta for a festive evening to celebrate the Federation's 25th Birthday! An elegant reception in the Skyline Room overlooking the Charles River will kick off the evening, followed by a spectacular silent auction, a special raffle of wonderful prizes, and an elegant dinner, awards, and entertainment.

Supported by generous contributions from local businesses, corporate sponsors, and individuals, the Gala is a time to applaud the accomplishments of the Federation and to recognize those of others. Senator Edward M. Kennedy will be honored for his national leadership in promoting public policies and programs that have transformed education and life opportunities for children and adults with disabilities, their families, and communities. Mary Richardson of WCVB TV's Chronicle is the Master of Ceremonies for this important event. Professor Gunnar Dybwad is honorary chairperson.

*Celebrating 25 years of
parents helping parents!*



Federation Workshops June 2000

JUNE 2000

6/8, Holyoke, 6:00 – 9:00 pm:

Basic

6/12, Northampton, 10:00 – 2:00 pm:

Basic/Transition/IEP

WORKSHOP DESCRIPTIONS

Basic:

Covers basic information about Chapter 766 and other state and federal special education laws to assist parents in the planning, decision-making, and monitoring of their child's IEP.
(Materials available in Spanish.)

IEP:

An in-depth look at the Team process of IEP development, with a focus on standards based education for all students.

Transition:

Provides basic information on state and federal laws which require that IEPs address goals in such areas as competitive employment, independent living, and full integration into community life that will help prepare students for adult life.