Partners in Policymaking Restored Our Independence!



This is a booklet giving testimonials about Partners in Policymaking.

Partners in Policymaking was created in Minnesota by the Governor's Council on Developmental Disabilities in 1987. Partners is an innovative, competency based leadership training program for adults with developmental disabilities and parents of young children with disabilities. The purpose of the program is twofold:

To teach best practices in disability, and to teach the competencies of influencing and communication.

Since 1987, Partners programs have been implemented in 30 states funded by the Developmental Disabilities Assistance and Bill of Rights Act.

More than 4,000 Partners graduates are part of a growing national network of community leaders serving on policymaking committees, commissions, and boards at local, state and national levels.

Documented program results show that *Partners* preserves families; and increases the independence, productivity, integration and inclusion of individuals with disabilities and their families into their communities. The value and success of the program, and the personal achievements of *Partners* graduates are evident in the testimonials that are contained in this booklet.



Alabama:

Partners in Policymaking received the LOTUS Award from the Women's Committee of Spain Rehabilitation Center. This is a most prestigious and competitive award.

From 1994 Partners graduates:

We protect the rights of the not so strong, to help them out when a right has gone wrong.

To make lives hurt free as we can, is what we'll do for any woman, child, or man. Our goal is simple, but it covers a very large ground, no one is forgotten, not for many roads around.

So if you're ever turned down, we'll fight your cause until justice is found.

Please give us a call and state your case; Partners will get on it, like running a race. Darryl is 45 years old and lives in a small, rural, home with his parents. Rarely did he travel very far; he had no friends, no dreams, no visions, no opportunities. After Partners, Darryl has begun to plan independent living options; investigate employment possibilities and step out of his home and into his community with confidence!

Arkansas:

We have had the opportunity to perform with the Naumburg Orchestra at Lincoln Center in New York City, but the performance we're most proud of is our involvement in Partners in Policymaking. Partners has directly affected our family's attitude toward and understanding of our son's abilities and capabilities. A long sought after communications breakthrough has occurred. The entire scope and mission of our lives have been changed by the Partners experience.

A fountain of information, an awareness that the rights of people with disabilities must be protected - this is what I learned from Partners. This will all be possible when the public is also informed.

Memorandum

My daddy is disabled due to a stroke and I am the mother of a daughter with a developmental disability and a son with a learning disability. Family Leadership Project provided the avenue to me to access programs and to understand the laws. It is a very worthwhile project that should continue!

California

Partners has made me critically think about how I need to raise my son so that he will achieve independence and a richer, fuller life.

Senate Bill 807 was passed because of the persistence of a Partners graduate. This law allows students to remain in school and The will regular to the secretion and the proof there of findings of a to provide graduate with their class even though they reach age 22 years.

I have been in an institution while of your thanks a few of the Hollings The communication of some south and collection, copy for most of my life. I got the protection represents the Marcheller is whom they talked myself a job at the local and he will see applied you to flow in a long of their shopping mall. (He now works at one of his regular from the companies of the first from a matter of the same of the same "hangout" stores). There I william might recovery by their History by yourse.

> Cinda-Rae has taken off! She facilitated a meeting with staff from Congressman George Miller's office addressing child care and respite issues; she also has been active in a program in Solano County working with families who have young children with disabilities.

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water worker which they got the the it is for the

Colorado:

I've surprised myself in the skills I've increased...I've met with a Senator and didn't feel powerless.

Partners has given me a sense of worth and the inner strength to move ahead!

Durante el curso de Colaboradores en Liderazgo, yo cambié de una persona que no se sentía cómoda alrededor de personas con desabilidades, a una persona que tienes muchas personas desabilitadas como amigos.

(During Partners I changed from someone who was not comfortable around people with disabilities to one who has many people with disabilities as friends.)

Since 1989, over 150 graduates have completed Partners training and have returned to their communities to become more effective advocates for themselves and their children.

Delaware:

As a trainee in the Partners program, I now have a framework to help me make a difference for people with disabilities. I testified at a Joint Finance Committee meeting of the Delaware State Legislature, and I spoke as a parent of a young child with a disability in support of continued funding. I was terrified but thanks to Partners, I had the courage to testify.

I was scared when I testified... no I was very, very, very nervous. I can only get better. More believe the WAP has racked delaware, and I do never the sound of forth out of the School of the WAP I the Stage of to the Year Finance

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Unfortunately, Delaware is one of those few states that does not have a statewide, comprehensive system of early intervention services. My three year old was not served by P.L. 99-457. I used to be angry that the parents before me did not advocate enough to get legislation passed, well now I am putting my anger to work.

Florida:

When I came here I was depressed and I only wanted to get out of the house for the weekend. Now my future is so bright I am going to need sunglasses.

A drop of rain is ineffective and easy to brush away, at Partners I have learned that rain is powerful. It becomes a stream of water that runs into a lake. The lake empties into a river and then goes to the sea. There is no logic in trying to stop the sea. When I speak to someone about my child's needs, I hear the roar of crashing waves and I guarantee, they will hear it too!



Good News for People with Disabilities

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Dear Friends:

Please send a copy of Action: A Manual to help you organize. If it is possible to send 22 copies, I would be thrilled. If that is not feasible I would be happy for a personal copy. I am currently taking a graduate course on transition and will be giving a session on supported employment. Your materials are wonderful and as a parent, an advocate, and a professional, I do appreciate them. You are also making me want to return North now so that my daughter can receive services there.

Thank You Elizabeth DeSousa

Georgia:

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arthers in

I am very hopeful for the future:
I see my son as happy, educated,
meaningfully employed, living
independently or with true friends.

I see him proudly taking his place in a community which cares about him and accepts him just the way he is.

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My focus has been widened beyond my hopes and dreams for his future. I have gained a great deal of insight and knowledge from presentations by experts in many fields: history of disability services, early intervention, inclusion, legal rights, housing, legislative process and lobbying. More important, the enthusiasm and activities of my fellow Partners has been a real inspiration to me.

The American with
Disabilities Act is, in my
opinion, the greatest thing
since the Civil Rights Act of
1964. Being both African
American and having a
disability, these laws have
definitely impacted the
quality of my life.
The sad part is it took
amendments to the U.S.
Constitution for certain
groups of Americans to be
treated fairly.

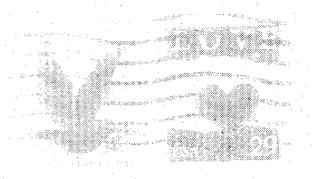
Hawaii:

We are even more committed to "go for it."

Partners has contributed to their community by running for political office, establishing support groups, serving on Councils, Boards, and Advisory Groups.

Two moms are advocates for the inclusion of children at the secondary level - new ground for many.

Another mom takes photos of locations in the community that are not accessible to her child who uses a wheelchair. She writes letters to increase access.



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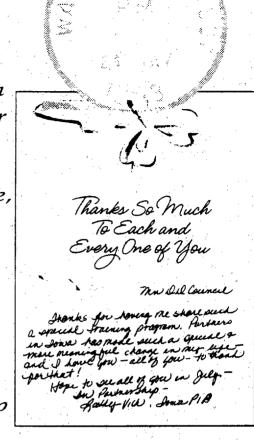
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Iowa:

A comprehensive family support program could help keep families together and offer an effective use of public dollars.

Family support services should be flexible, individualized and designed to meet the diverse needs of the family,

It is time for the state of Iowa to declare that it values families in the life of children with disabilities. It it time to give financial support to the family instead of the state institutions and group homes.



Mission Statement:
It is the mission of Partners in Policymaking to transform the formal training, information, and resource materials into education, support, and action in our communities.

Illinois:

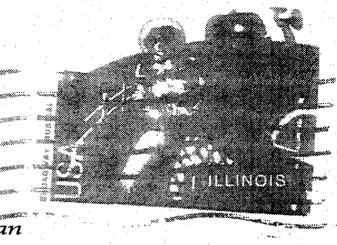
Partners strives to educate, enhance, and empower people.

Partners has showed me how I can and must become part of the change in our society to include all people.

We learn "how to" build constructive partnerships.

As I sat through Partners sessions, I wanted to believe everything that the speakers said. I was skeptical. Then my daughter's educational placement was described - a street that goes nowhere, stairs that go nowhere, preschool toys, and five nonverbal children together.

Now she's included in general education and her eyes sparkle and her face beams with pride. She is happy and proud.



Partners has allowed me to dream again...to dream about my son the way all parents dream about their children. Partners has showed me how I can and must be part of the change in our society as we build a system that includes all people.

Indiana:

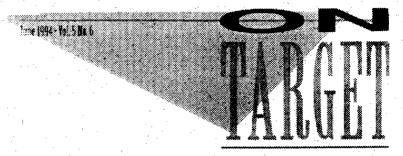
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I was already an advocate, but Partners increased my knowledge about the legislative process, the ADA, and other issues. My credibility has improved among government and business leaders. I'm consulted on disability issues.

I had no idea of the opportunities available to people with disabilities.

Now I sit on several boards and am an active advocate for the issues that are important to me.

I cannot say enough good things about Partners.
I learned more in eight weekends than I have in eight years of inservice workshops.



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inclusion manual available to educators (52/)

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Monthly publication of the Indiana Governor's Planning Council for People with Disabilities

Louisiana:

Everyone is beautiful in his/her own way. I have seen kids with disabilities exhibit more determination, more fight, and more guts than I could ever possess.

My greatest regret is that it took so many years to realize that I was an equal and very important partner in all decisions concerning my son.

Partners is the most impressive and dynamic movement on behalf of people with developmental disabilities to ever occur.

Partners will be the driving force behind full inclusion for all.

24 Karen Lane Monroe, LA 71203 September 2, 1992

Dr. Colleen Wieck Minnesota Governor's Planning Council on Developmental Disabilities 300 Centennial Office Building 658 Cedar Street St. Paul, Minnesota 55155

Dear Colleen:

The Summer Training Institute in Minnesota was wonderful! I wish all the LA 1991 Partners had been able to attend. It was such a rejuvenating experience. I truly believe that we need annual reunions to bring us up to date on legislation, new services, etc., and just to pump up our motivation! The faculty for the institute were very motivating. It was great to see Fran Smith, Ed Roberts and Sue Swenson again. Deborah McFadden is a wonderful speaker. We are indeed well represented in Washington.

My participation in Partners made me realize the importance of public awareness and understanding of persons with developmental disabilities. Prior to the movie "Rain Man", there was very little public awareness of Autism. My first goal after Partners was to enhance public awareness of autism and to increase my community's understanding of this developmental disability and therefore facilitate acceptance of persons with autism. The establishment of a local chapter of the Autism Society of America seemed a logical step to provide future support and resources for persons with autism in this area. Armed with knowledge gained through Partners and after several months of planning, I began my campaign to establish a local ASA chapter in February 1992. On May 4, 1992, with fourteen charter members, the Northeast Louisiana Chapter of the Autism Society of America became a reality. I now serve as president of this group.

Shortly after completing my Partners training, I was invited to attend a parent training session by Project PROMPT (Parents Reaching Out - Model for Parent Training). As a result of this contact, I became involved in afforts to establish a state-wide network of family-directed resource centers, specifically for families of persons with developmental disabilities. It is the mission of this Family Resource Network to enable and empower Louisiana families of special needs through a coordinated network of resources, support, and information exchange. An experienced and informed family of a person with a developmental disability is an extremely valuable resource to the family of another person with a developmental disability. Such support and understanding are not available any where else. I am now serving as chairman of the Board of Directors for Families Helping Families of Northeast Louisiana, as our Region VIII resource center is now called.

Minnesota:

I find myself much more able to cope.

I find myself looking long term and setting goals and priorities. "Fixing"

Michael's academic problems which were so important one year ago are secondary now. More important is self concept, socialization, integration and independent living skills.

For me, being able to communicate with policymakers has diminished the underlying rage I have experienced for so many years due to my Anishinabe heritage.

If I could break down one barrier for people with disabilities, it would be other people's first impressions.

James Anderl is twenty-one. He attends Normandale Community College and enjoys math and science more than English or humanities. He currently has a class in American Government and said that it's frustrating to learn that out of the 10,000 bills that have been introduced in Congress only 500 to 700 actually have become law. James has cerebral palsy.

Missouri:

To hear people talk about what I dream about for my child was great. I have so much information and my horizons have broadened to include so much more. It's scary, sobering, and thrilling.

Partners has enabled me to continually search for knowledge and with that knowledge I hope to become a catalyst for change.

Beyond the confidence and knowledge you come away with, there are the true partnerships.

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I take this opportunity to say thank you for letting me be a part of Partners in Policymaking graduation weekend. It was a weekend I will keep in my heart for a very long time.

Sincerely,

Jesse Jones, III

Montana:

Understanding the system, how to access the system in the appropriate way, how to affect positive policy changes - this knowledge will better prepare parents to properly make system changes and improve the quality of the lives of our children. Partners gave me unquestionable gains in my knowledge of the system, how to advocate for my two foster sons, and contribute to enhancing the opportunities for all individuals with disabilities to achieve independence.

At a time when everything in our personal lives seemed bleak and hopeless, and we lacked support and knowing how "the system" worked, Partners made it possible to regain some self-worth and patch up a pretty banged up self-esteem. I now have the tools to be effective in implementing our goals for our son, to change fear into opportunity and work within the systems to make decisions. Dare to dream...that Partners not only will make a difference, but is the difference.

Partners is an effective and powerful effort because it combines national and local expertise. Parents with their years of experience in the developmental disabilities system, coupled with Partners training, results in knowledgeable and focused leaders for our state.

Nebraska:

Partners was a big shock for me. I always felt isolation was better so people with disabilities wouldn't take teasing and abuse. I view individual plans differently.

My plan of action includes election to the Arc Board and developing closer contact with public officials.

I now have more control in my child's future in school and there's no reason not to speak out about concerns.



I didn't know Adult Basic
Education was even
possible for my daughter
who is currently out of
school, unemployed and not
receiving any services.
Partners taught me a lot,
now my daughter has
started classes and we both
are feeling very hopeful.

New Hampshire:

I now feel confident to make informed and good decisions. I am not afraid of asking for help.

Our family is changing. We purchased a computer and added onto our house to give our son the privacy he needs.

I learned independence...I can talk for myself and not have someone talk for me. I have become aggressive and know when to use my power.

I am so much more informed, encouraged and strengthened.

A statewide telephone network was established after the first Leadership Series in 1988 and grows annually with each series. This network is activated whenever a political issue or information sharing is identified that may affect families or individuals with disabilities.

New Mexico:

I want to be a model for my seven year old daughter with cerebral palsy. I want her to know that she has a voice and should have the tools and self esteem to use it.

Partners are making changes in their communities. I don't feel powerless.

Self-advocates seek crosswalks with signals, a lengthened walk period, pedestrian over pass, or alternative signals for people who are blind when a friend with developmental disabilities was killed crossing a street.



Diversity is important.

Most of us now see that all people are people first with needs and rights. We all want to enjoy life, to feel productive and secure.

New York:

Partners are the national guard.

In 1991-1992, the family support budget was restored. Family support legislation was enacted. Partners are serving on the State Advisory Council.

Having a child with a severe disability was like having a grenade lobbed into the serenity of our family life. Everything in our life exploded. After one weekend of Partners, I came home and said, "We're going out to dinner." I didn't mind the stares because I'm a member of this great club united, strong, and working for changes.

In 1992, a Partners graduate wrote to Fisher Price to ask why children with disabilities weren't included in the catalog. The company responded by inviting her son for a photo shoot. Children with disabilities are now regularly featured in their catalogs.

Anastasia Somoza was a television star on February 20, 1993 when President Clinton met with 30 children from the United States. Anastasia was the only child to have a disability. She nearly moved President Clinton to tears as she explained how her sister uses a computer to communicate and she wants her to be in the same classroom.

The New York City Public Schools have fought against inclusion.

North Carolina:

The program gave me a chance to learn more about disabilities and how I can improve the conditions in society by being a part of society. It made me feel important and it also gave me a greater sense of self-confidence.

When I think of a Partner, I think of someone who walks with you through thick and thin regardless of the situation.

Partners has opened my potential to be an informed, aggressive advocate for my family and community.

I learned about the different connections you can use to get things done. I enjoy talking to people with the same problems, working together so that things are less difficult.

Partners is an experience that has really changed my life! I feel much more in charge and more able to handle bureaucratic mumbo-jumbo. I am less intimated by people in authority and I finally believe they are neither monsters nor superheroes, but just people in jobs where they may or may not be doing well. My job now is to keep track of how well they do concerning my interest.

North Dakota:

My son was totally isolated and didn't like school. Because of Partners, my son is the model of inclusion; he is happier and has more friends than I dreamed possible.

I received valuable information and inspiration needed to advocate for all people with disabilities.

The equivalent of a master's degree in disability and advocacy. Partners has challenged my perceptions and given me a clearer sense of direction.

I now feel differently about my child; it doesn't matter to me that he has a disability. I look at him as equal to others.

Thank you for the knowledge, experience, "fire," and compassion.

When I came to Partners, my daughter's education program was a mess. I could not understand why she didn't like school. After a few sessions, I learned how my daughter probably felt. I then learned what to do and how to do it. Partners has been the clear road to my daughter's success and happiness.

Ohio:

Thirteen families met with a U.S. House member to discuss health care reform.

We were named foster family of the year by our county. I have served on the state early intervention committee.

We designed a curriculum about disability awareness. The slide show depicts children and families who are differently abled. The impact has increased understanding among nurses, social workers, administrators, parents, and teachers.

Over the past year, Chris had spent a good part of his school day in regular classrooms and has begun to use facilitated communications with assistance from the school staff. Tested two years earlier, Chris scored a 28 on an I.Q. test. The latest evaluation, using facilitated communications, resulted in an estimated score of 133.

Oregon:

1994 Class
Our vision of the future:

Families and consumers are involved in policy and budget development.

Supports are designed for an individual, not as a service system.

The State of Oregon recognizes that families constitute the largest provider system in the state.

Families and consumers have a choice in the design and selection of supports.

Families and consumers participate in evaluating services.

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Pennsylvania:

I believe I will be able to participant in those areas of the movement that I have interest in more fully and also be able to listen to different view points without disdain.

I think I am more confident about how I present myself and my wishes. I'm not nervous about talking to politicians now. I also think I'm angrier, more militant, and less able to keep my mouth shut when I see inequities. Hopefully, I'll find a way to "use" my anger constructively.

I am now president of a Family Support Group. I prepare and distribute a one page, three column newsletter, along with other pertinent information to a mailing list of over 50 families and over 15 others. including providers. interested professional. and educators. We have provided information to schools. I feel much more comfortable in writing or otherwise contacting legislators. I don't have to be an expert, attorney, or professional. My knowledge as a parent and advocate is valuable and I am a powerful and convincing spokesperson.

South Dakota:

One of the graduates lived in a group home. After graduation, she purchased her own home.

Partners attended a series of town meetings around the state. The state agency staff wanted to know if the coordinator had worked with one witness all day to prepare her. No, we didn't coach her. She's a Partners graduate.

I was doing piecework at a sheltered workshop. I decided to go back to school to become a secretary. The difference was self esteem. Partners saved my life. I used to be on psychotropic medication. I started asking questions, decided to say no and took control of my life.

Tennessee:

It's about having a vision and then finding ways to enact that vision in tangible outcomes.

Partners includes civics, confidence building, and grassroots radicalism.

My participation in the Partners program was a positive experience. This experience has raised the level of my involvement in both the legislative and community development arenas. The leadership training I received improved my ability to address the issues that people with disabilities face from the standpoint of an informed advocate.

Being a member of Partners in Policymaking has taught me that we who "know" can make a positive difference in the policies that affect us or our children. It turns the helpless, powerless feelings into knowledge, influence and change. Izhtak Periman, noted international violinist:

One has to separate one's abilities from one's disabilities. Some people looked on me as sweet, a human interest story, that's what I had to work to overcome. Even with all the regulations, accessibility at concert halls is still a crap shot.

Excerpted from *Breaking Ground*, a newsletter of the Tennessee Developmental Disabilities Council.

Texas:

I have enjoyed participating in the Partners class so very much, I am looking forward to putting my new knowledge to work. You have created a wonderful and necessary program that I am glad to have had the opportunity to attend and benefit from the fabulous resources, wisdom and information you presented.

I finally have wheels. After a wait of over 2 years I received an adapted car in September. I have a permit so now I will take lessons. Persistence pays off!

The information was invaluable. I now understand why it is so derogatory to use the "H" word.

Lettitia Clay, San Angelo, TX

After Partners, I was a changed person. I set to work on creating what was best for Rodney and our family. After some struggle, we got Rodney into a regular third grade class, he got help from staff and other kids. His behavior problems faded away quickly. It was then it dawned on me that Rodney had been bored with no role models. Now he is learning, taking part in school activities and making friends.

Utah:

I was given the opportunity to become a Partner and this outstanding program opened my eyes to the many different types of disabilities and disability issues. The training sessions and guest speakers provided an outlook of the necessity for people with disabilities to become active in changing and supporting programs and services that will improve their lives.

The Partners experience has provided me with sound knowledge about disabilities and how to give individuals with disabilities the ability to mature and change their lives and to enable the parents of children to support and meet the challenges facing them.

The time that I spent in Partner was wonderful. I was taught what services are available and how to utilize them. It has given me the confidence and knowledge to stand up for myself and others.

A year or so ago when someone asked me if I had Family Support, I thought they were asking if my parents or family members lived close by. Then I heard about Partners. I applied and what I learned changed my life and the life of my child forever. I now have a family support trainer that does community activities with my son weekly and also respite care so my husband and I have some time together.

Virginia:

I have been an advocate for my son for the past ten years; now I know how to do it right!

Partners has given me a road map to follow which has enabled me to successfully navigate through the system. I finally feel like I am in control, I have been empowered

The skills learned in Partners are lifelong, and I am always going to need and use them. As a result of those skills, I successfully got my son into a summer parks and recreation program.

Washington:

The information I received gave me confidence to advocate for my daughter. Knowledge is a powerful tool.

I was determined to go back to school to receive my G.E.D. I have more confidence in asking and seeking what my girls need and deserve. I ran for the School Board and will try again this fall.

This was a once in a lifetime opportunity to receive an enormous education in a few weekends. It provided me with confidence, assurance, poise and determination that I too can make a difference for people with developmental disabilities.

Just a few people truly can make effective changes.

Intense education about disabilities.

The other participants played a key role in teaching. We shared our unique experiences.

West Virginia:

Partners brings us together, instills selfconfidence to become active participants in advocating for our rights.

Partners opened a lot of doors for our son's future and showed us he can live a full life given the chance.

I have learned to speak out for people who are disabled and to stand up for our rights.

Partners was a very good experience, I learned a lot, had fun, got to know other people from around the state.

Partners revitalized!

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Shirley Klein, a computer specialist, recently traveled to England and had this to say:

My trip has made me realize that we must not only work to preserve and implement the ADA in this country, but we must also strive to ensure these hard won rights are realized by people with disabilities throughout the world.

For more information, contact:

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